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Disability Policy in the U. S.:
Current Challenges and Future Opportunities

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Disability Policy in the U. S.:
Current Challenges and Future Opportunities

by

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Abstract

Disability Policy in the U. S.:
Current Challenges and Future Opportunities

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Nearly a quarter of a century after the passage of the Americans with Disabilities Act (ADA), people with disabilities remain severely under-employed. All the while, they command a disproportionate share of public monies through Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI). This report seeks to contribute to the conversation on current disability policy, as well as offer short-, mid-, and long-term solutions.

The document opens with a history of the Social Security Administration (SSA), the federal agency responsible for setting national disability policy. This is followed by a discussion of SSA's primary categories of client support: health care and employment initiatives. The health section details the medical coverage attached to both SSDI and SSI, with a particular focus on the Affordable Care Act (ACA). Next is a review of work incentives offered to SSDI/SSI beneficiaries. Concluding this chapter is an investigation of the causes of under-employment that continue to plague the disabled circle, in spite of these many interventions.

The study continues by exploring various issues affecting today's U.S. disability policy. These include both exogenous and endogenous factors, including the growth of SSDI and SSI; the structural issues inherent to the current paradigm, as well as a number of disincentives to employment.

The analysis then turns to disability policy in the international community. Of particular interest are the experiences of Sweden and the Netherlands as they established fiscally sound policy while assisting the nation's disabled. From these case studies emerge several lessons pertinent to the U.S. This chapter closes with a thorough analysis of these European nations' responses to their ever-growing disability programs, and the implications for disability policy makers and advocates.

Concluding the report are several recommendations that can guide policy makers and advocates as they strive to place the disability community on the path to self-sufficiency. Most relevant and promising to the U.S. are the passage of the ABLE Act, instituting a national Medicaid Buy-In, and establishing a central disability agency.

With successful implementation of these reforms, American with disabilities can potentially finally realize what the ADA promised 25 years ago.

Table of Contents

List of Figures

Introduction

Disability advocates, congressional leaders, academics, and tax payers are in unanimous agreement that U.S. disability expenditures are rising at an unsustainable pace (Burkhauser & Daly, 2013; National Bureau of Economic Research,. Since 2009 the Social Security Disability Insurance (SSDI) program's annual outlays have 2006) consistently exceeded tax and interest receipt. Should this continue, experts caution that the fund will reach insolvency by 2016 (Segelken, 2014). Its sister program, Supplemental Security Income (SSI), has provoked alarm as well. Since its inception, the growth of child participants has multiplied more quickly than the overall program (SSA, 2011). Many have debated the root causes of these two phenomena. Disability programs are under particularly close scrutiny, primarily for two reasons: the recent influx in enrollees with disabilities, particularly those with mental impairments; as well as the corresponding low rates of the labor force participation of these challenged individuals (Vallas & Alfano, 2012).

While many policy officials and the Social Security Administration (SSA) argue that the heart of the matter lies in the appropriate allocation of public monies, those in the disability community hold a very different vantage point. The National Disability Council (NDC) decries that a mere 18.7% of people with disabilities participate in the labor force as compared to 68.3% of individuals without disabilities (Rosen, 2014). Other activists have pointed out that our present disability paradigm damages not only U.S. taxpayers, but also individuals mired in a "benefits trap" who can do little to positively alter their economic standing and career path under the current system. All the while, federal and state disability expenditures continue their upward trend. In 2013, taxpayers spent $873 billion supporting this vulnerable population (Edwards & DeHaven, 2013).

Chapter 1: Background of U.S. Federal Disability Programs

GENERAL HISTORY

In 1956, the SSA was charged with safeguarding individuals with severe work-limiting physical, mental, and emotional impairments from financial devastation (SSA, 1986). This governmental entity fulfills this responsibility through a framework of support, comprised of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) (CBO, 2012). These two programs are distinct, yet share important intersections. In both, disability is statutorily defined as "the inability to engage in substantial gainful activity (SGA) by reason of a medically determinable physical or mental impairment expected to result in death or last at least 12 months" (SSA, 2014, n.p.). Additionally, SSI and SSDI applicants are subjected to the same application and disability determination procedures. Following a five-step framework, client eligibility is jointly determined by federal and state officials. Here, SSA staff considers a person's current employment (or lack thereof), severity of impairment, as well as vocational factors. Denial can occur at any stage (Moulta-Ali, 2012). Soon after a person is certified as "medically disabled", they are entitled to collect monthly income support from SSI or SSDI, or, in a few cases, both concurrently.

OVERVIEW OF SOCIAL SECURITY DISABILITY INSURANCE

Falling under Title II of the Social Security Act, SSDI was first enacted in 1935 as a social insurance program for those with a recent and significant history of employment, and in poor health (SSA, 1986; Moulta-Ali, 2012). As the ruling originally states, a person must have participated in the workforce five of the previous ten years. Shortly thereafter, cash benefits were extended to younger disabled workers, and in 1973, health coverage was added as an entitlement under Medicare (O'Brien, 2009).

Today SSDI covers adults under the age of 67 who have formerly been employed, but are now unable to work due to a health condition that is anticipated to continue for longer than twelve months or result in death. Receiving benefits also entitles spouses to benefits, provided they are 62 years or older or if they are the primary caretaker of the

recipient's biological child. Finally, a beneficiary's child or grandchild may also collect benefits under the condition the minor is unmarried, is under 18; is a full-time student, *or* has a disability that commenced before age 22 (SSA, n.d.).

Monthly allotment is calculated relative to a prior employment record. In 2012, SSDI supplied each beneficiary with an average of $1,111 monthly (CBO, 2012). In accordance with SSA regulations, employed participants may only earn up to a specified amount. Should they exceed this benchmark, their benefits are automatically terminated and cannot be reinstated until wages drop below the pre-determined level and a period of five months elapses (O'Brien, 2009). An individual may only receive benefits until they reach the full retirement age. Once persons reach this milestone, they are automatically admitted to the Old-Age and Survivors Insurance (OASI). This status change does not affect their monthly stipend in any manner.

The Social Security payroll tax is primarily responsible for financing the SSDI program. While in the workforce, both the employee and his employer contribute to the fund on a monthly basis. Depending on a specific fund's financing needs and current economic conditions, Congress has the authority to distributed the total payroll tax between Old-Age and Survivors Insurance Trust Fund (OASI), and DI as it deems fit (Ruffing & Water, 2014) .

OVERVIEW OF SUPPELMENTAL SECURITY INCOME

Upon the enactment of the Social Security Act of 1935, disability activists immediately began clamoring for a separate, needs-based paradigm offering assistance to the disabled at both ends of the age spectrum (SSA, 1986). Fortunately, the originators of the law made provisions for similar safety-nets to be instituted for physically, mentally, and emotionally challenged citizens. Some of the entities involved were Old-Age Assistance (OAA), Aid to the Blind (AB), and Aid to the Permanently and Totally Disabled (APTD). These anti-poverty initiatives were governed primarily by state and local agencies, and "jointly funded" with the federal government "under a grant-in-aid

arrangement" (Ozawa, 2002, p. 153). Over time, these programs became increasingly more convoluted and overlapping. At one point, these were among the "1,350 administrative agencies involved [who made disability] payments varying more than 300% from state to state" (SSA, 1986, p. 4).

Wishing to untangle this administrative quagmire, Congress federalized the means-tested SSI program in 1972, which consolidated the prior state programs and substantially reversed the roles of the federal and state entities in terms of adult disability assistance. This new paradigm mandated the federal government provide a standard minimum income while states were free to establish supplementary levels as they saw fit.

Since the early 1970s, the number of SSI clients has slightly more than doubled. Also, during that time the share of disabled clients has risen steadily, as compared to those receiving SSI on the basis of age. Today, it is viewed as an increasingly vital safety net for the disabled community. Indeed, a majority, 86%, register on the basis of disability. And among those claiming disability, six out of every ten report having a mental impairment (CBPP, 2014). Despite the disabled community's disproportionate share in the program, elderly individuals age 65 or older may, and often do, enroll, when they have very little income and/or assets (DeHaven, 2013).

Today SSI is considered the assistance of last resort and stands as a national program that guarantees a minimum income floor for Americans who own very few resources. In January 2013, 8.1 million individuals received monthly payments averaging $507, an increase from 7.9 million recipients with an average payment of $497 from the previous January (SSA, 2013). This stipend is often accompanied by Medicaid, Supplemental Nutrition Assistance Program (SNAP) enrollment, and housing assistance (DeHaven, 2013; D. Warner, personal communication, August 6, 2014). For nearly 60%, a monthly SSI payment represents their sole means of financial stability. Households with an SSI beneficiary often reside below 150% of FPL, in spite of the income supplement. While SSI is not able to thrust persons above the poverty line without the

support of other public assistance, it has proven successful in rescuing persons from the depths of extreme poverty.

Unlike SSDI, financing for SSI comes from the general revenue fund and is collected through the U.S. Treasury Department. In fiscal year 2012, federal SSI payments cost the American taxpayer slightly over $50 billion or 1.4% of total US spending for the year (CBPP, 2014).

When evaluating a potential enrollee, SSA initiates a thorough review of a person's accumulated assets. For these purposes, assets are defined as savings in a bank account, personal property, life insurance policies of $1,500 or less, stocks and bonds, etc. Not categorized as assets, and thus not included in the initial assessment, are an individual's primary residence and one vehicle. As long as an eligible person possesses no more than $2,000 in countable assets, he or she is admitted into the program and can start receiving benefits soon after (AARP, 2012). This $2,000 limit has not been updated since 1989 and is not currently tied to inflation (Moulta-Ali, 2012).

The following chart provides a concise summary of the distinctions between SSI and SSDI.

Comparison of the SSDI and SSI Disability Programs

	SSDI	SSI
Source of payments	Disability trust fund.	General tax revenues.
Minimum Initial Qualification Requirements	Must meet SSA's disability criteria. Must be "insured" due to contributions made to FICA based on your own payroll earnings, or those of your spouse or your parents.	Must meet SSA's disability criteria. Must have limited income and resources.
Health Insurance Coverage Provided	Medicare. Consists of hospital insurance (Part A), supplementary medical insurance (Part B), and Medicare Advantage (Part C). Voluntary prescription drug benefits (Part D) are also included. Title XVIII of the Social Security Act authorizes Medicare.	Medicaid. A jointly-funded, Federal-State health insurance program for persons with limited income and resources. It covers certain children, and some or all of the aged, blind, and disabled in a state who are eligible to receive federally-assisted income maintenance payments. Title XIX of the Social Security Act authorizes Medicaid. The law gives the states options regarding eligibility under Medicaid.
How do we figure your monthly payment amount?	We base your SSDI monthly payment amount on the worker's lifetime average earnings covered by Social Security. We may reduce the amount if you receive Workers' Compensation payments (including Black Lung payments) and/or public disability benefits, for example, certain state and civil service disability benefits. Other income or resources do not affect your payment amount. We usually adjust the monthly payment amount each year to account for cost-of-living changes. We can also pay SSDI monthly benefits to dependents on your record, such as minor children.	To figure your payment amount, we start with the Federal Benefit Rate (FBR). In 2012, the FBR is $698 for a qualified individual and $1,048 for a qualifi d couple. We subtract your countable income from the FBR and then add your state supplement, if any. We do not count all of the income that you have. The income amount left after we make all the allowable deductions is "countable income". The sections on SSI employment supports explain some of the ways that we can exclude income. We usually adjust the FBR each year to account for cost-of-living changes.
Is a State Supplemental Payment provided?	There is no state supplemental payment with the SSDI program.	Many states pay some persons who receive SSI an additional amount called a "state supplement". The amounts and qualifications for these state supplements vary from state to state.

Figure 1. Comparison of the SSDI and SSI disability programs. Reprinted from 2012 Red Book, Social Security Administration, 2012. Retrieved June 21, 2014, from http://www.socialsecurity.gov/redbook/eng/The%20Red%20Book%202012.(F).pdf

Chapter 2: Current Program Offerings: Health Care

In addition to providing a level of financial security each month, SSA offers beneficiaries a number of other initiatives to assist them in their quest toward financial independence. These fall under two major categories: health care provisions and employment supports. Health care will be detailed in this chapter, while employment supports will be the focus of the next chapter.

HEALTH CARE PROVISIONS

Individuals with disabilities often face significant health care needs and resultant high medical expenses. As a result, these challenged individuals frequently require services such as long-term care, social supports, case management, attendant care, therapies, mental health care, and durable medical equipment. Unfortunately, in most private plans these specialized services are characteristically covered only to a limited extent or not at all. Further, Medicaid is the dominant, and often times the only, source of financing for long-term care and home- and community-based services (HCBS), a critical weapon in the struggle against institutionalization. Therefore, the health insurance attached to SSDI/SSI is of paramount significance.

Both federal disability programs offer health care provisions, yet the pathway to coverage differs. SSDI provides coverage through Medicare, while SSI grants access via Medicaid. The SSDI insured gain health coverage from Medicare after a 24-month waiting period, which is in addition to the five-month waiting period for general SSDI eligibility, a total of 29 months. Contrarily, SSI participants gain health insurance almost immediately.

Medicare for SSDI beneficiaries

In 1972, Medicare coverage was added to benefits extended to persons under the age of 65 with disabilities and enrolled in SSDI. After the designated waiting period, individuals entitled to this disability program are eligible to the full range of benefits that

Medicare provides: hospital care, physician services, and prescription drugs. But unlike the comprehensive coverage of Medicaid, Medicare does not provide many of the services important to persons with disabilities. Similar to private insurance policies, Medicare is less compatible with the health needs of this population because it excludes long-term services and supports as well as extended therapies that can be vital to regaining independence

Despite their glaring need for medical care, a significant number of *new* SSDI beneficiaries are uninsured and remain uninsured until Medicare begins at the end of the waiting period. An equal share, mainly those who are low-income or those whose medical expenditures are large, are able to enroll in Medicaid during the waiting period. A final group secures coverage through employer plans. Under COBRA rules, employers offering health insurance plans are required to offer disabled workers the option to continue their health insurance while waiting for Medicare coverage to begin. Disabled workers may be required to pay hefty premiums to retain their former employer's plan, thus deeming it unaffordable to the large portion of SSDI enrollees who have now have little income.

There are many vocal critics of the 29-month medical deferral period (the 5-month initial program wait added to the 24-month period for Medicare). This program feature often forces impaired workers to compromise their health during a critical time in their recovery. In fact, studies demonstrate that "death rates among SSDI recipients are highest during the first two years of enrollment" (Medicare Advocacy, 2005). And many SSDI participants neglect treatments or forego medications in this time when health care could stabilize their condition. Having to wait for these supports further separates beneficiaries from the work force. In a recent year, an estimated 1.8 million SSDI beneficiaries were left in this waiting period (Medicare Rights, 2008).

This is an unfortunate situation since individuals who are recently disabled have the strongest attachment to the workforce and thus are most likely to be successful in

returning to work. Research in the field of disability management suggests that the longer ill or injured employees remain on disability leave, the less likely they are to ever return to work (She & Livermore, 2007).

Once through the 29-month period, Medicare often becomes a lifeline that substantially improves access to and affordability of health care to this population. However, due to its significant cost sharing requirements (premiums, deductibles), most beneficiaries need supplemental health coverage to fill Medicare gaps.

SSDI beneficiaries keep their Medicare coverage for as long as they remain disabled. As will be addressed later, SSDI employment incentives allow beneficiaries who return to work to keep their Medicare coverage for up to 93 months. There are also options under which they may purchase coverage in a Medicare Buy-In, provided they remain medically disabled.

Medicaid for SSI beneficiaries

Medicaid is especially appropriate in this context because it offers comprehensive and wide-ranging services typically needed by the SSI population. Often awarded to beneficiaries at no cost, eligibility is granted one month after qualifying for SSI cash payments (Social Security Online, 2014). In 39 states and the District of Columbia, those who qualify for SSI are categorically eligible for Medicaid. And in many cases, applying for SSI automatically begins consideration for Medicaid. Eleven states (Ohio, Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, Oklahoma, Virginia, and North Dakota) have Medicaid eligibility criteria that are more stringent than the federal program (Kaiser Family Foundation, 2010). SSA permits these more rigorous state requirements provided they "are no more restrictive than the state's January 1972 medical assistance standards" (SSA, 2013).

Lastly, Medicaid offers long-term services and supports that can allow "millions of people with severe physical disabilities to lead productive and independent lives". And the availability of such services often dictates the potential of [SSI recipients] "to be

employed and to be active participants in community life, regardless of the individual's inherent capability to achieve these goals" (Nosek, 1991, p. 2.).

THE DISINCENTIVE EFFECT OF MEDICAID AND MEDICARE

To the dismay of disability advocates, Medicaid and Medicare are inextricably tethered to the overall benefit packages offered by SSI and SSDI. They argue this link serves as a disincentive to seeking competitive employment and exiting the rolls of SSI/SSDI. One study explained:

> Despite the good intent on providing [public] health insurance to persons with disabilities, research suggests that existing eligibility criteria for public health insurance create significant employment disincentives that [first] encourage[s] people to enroll in disability programs and [secondly] discourage[s] them from leaving the programs and returning to work" (Levy, Bruen, & Ku, 2013, p. 104).

Findings reveal that "this disincentive effect is markedly stronger for people" with significant health care requirements, particularly those who deem private insurance of "limited value relative to their health care needs" (Levy, Bruen, & Ku, 2013, p. 104).-

Validating this is a recent survey of SSDI and SSI beneficiaries that suggests that "fear of losing health benefits is the most important reason they are reluctant to return to work." The SSA currently offers multiple work incentives that will allow participants to temporarily retain their health coverage when reintegrating in the workplace. However, the same study revealed that 85% of SSI and SSDI participants are aware of these initiatives for continuing health care" (Levy, Bruen, & Ku, 2013, p. 104). Yet few take advantage, demonstrating how strong this apprehension is.

THE INFLUENCE OF THE AFFORDABLE CARE ACT (ACA)

The ACA has spurred major changes in the U.S. health insurance market, many of which promise to improve insurance outcomes for working-age people with disabilities. Some of the provisions most relevant to individuals with disabilities include prohibitions on denying coverage or increasing premiums based on health status, bars on use of

preexisting condition exclusions, guarantees on renewability of coverage, prohibitions on lifetime and annual maximums, limitations on cost sharing and the mandated coverage of essential health benefits. The health care law will tear down a number of the obstacles to private health insurance that people with disabilities typically confronted in the past (Levy, Bruen, & Ku, 2013). Additionally, in states that elected to expand Medicaid, the ACA has created two new forms of public health coverage for working-age adults: Medicaid eligibility for working age adults with incomes up to 138% of poverty as well as subsidies for people with incomes up to 400% of poverty level to purchase coverage through the newly created state health insurance exchanges. It is possible that these provisions of health reform will reduce the employment disincentives for workers with disabilities and encourage SSI/SSDI exit (Levy, Bruen, & Ku, 2013).

The ACA and Medicaid

ACA's impact on those mildly disabled will likely be significant. But these individuals were not qualified for SSI or SSDI to begin with. The impact, if any, on individuals with disabilities significant enough to qualify for federal assistance and who require wider and specialized services such as those covered in traditional Medicaid is much more difficult to estimate. Anything less than traditional Medicaid will likely be of little value to the 11 million Americans, or 22% of those with disabilities, who require personal assistants to assist with activities of daily living (ADLs) (PBS News Hour, 2010). Therefore, the impact of the ACA on this population will likely be minimal.

These options may reduce fears related to the loss of employer-sponsored coverage, allowing disabled workers to move between jobs or into self-employment. The ACA may also give SSDI and SSI beneficiaries a greater incentive to attempt a return to work because eligibility, for public health insurance coverage is no longer tied solely to an inability to engage in substantial gainful activity.

Yet, there are several ACA policy implementation issues that will affect the extent to which it improves health insurance coverage and creates employment incentives for persons with disabilities enrolled in SSI/SSDI:

1) The wide range of benefits states can elect to offer under expanded Medicaid and in the ACA marketplace: New Medicaid participants must enroll in benchmark coverage plans. Federal guidance permits a variety of options about how states define those plans. If they are limited in nature and do not include the therapies, supports, and treatments critical to people with disabilities, expanded Medicaid may not be the optimal substitute for the traditional Medicaid coverage linked to SSI eligibility.

Alternatively, in the newly created state insurance exchanges, health insurance plans must offer "essential benefit packages", yet states will have considerable discretion in defining the contents. The combinations selected will ultimately dictate how well state insurance plans meet the needs of persons with disabilities.

2) The extent to which the federal and state governments will engage in outreach and public information campaigns to inform people with disabilities about new sources of assistance in obtaining health insurance: As an example, research evaluating state Medicaid Buy-In programs, specifically intended for workers with disabilities, reveal poor return-to-work rates, a direct result from diminished awareness (Levy, Bruen, & Ku, 2013).

The benefits available in these new state plans will strongly dictate the rate of participation in the ACA by individuals with significant disabilities. Yet, at this time, there exists little literature regarding the extent of benefit coverage offered by expanded Medicaid and the Marketplace. This is explained by the newness of the program. Therefore, in-person and written interviews were conducted with a range of local experts

in this field. The variety of backgrounds among these professionals was an attempt to tap into different views and a variety of perspectives. These conversations included the senior policy analyst for health care at the Center for Public Policy Priorities (CPPP), the Operations Coordinator from Foundation Communities (Insure Central Texas division), and the Executive Director and leader of My Medicaid Matters from ADAPT, a local grassroots disability organization.

While all of these experts cautioned that it was too early for judgment, there was consensus that it was highly likely that new health care opportunities created by the implementation of the ACA would not cover many of the needs of severely disabled persons, most especially attendant care services, long term employment supports, a high level of habilitative services, etc.

The policy expert advised "I think the ACA didn't affect the identified problem at all." Many gaps between traditional Medicaid, as offered to SSI enrollees, and commercial plans were NOT closed by the ACA. "Attendant care services and other long term care services and supports are good examples" She advised that in fact the new ACA plans likely "specifically excluded" many of these disability-related benefits (S. Pogue, personal communication, July 23, 2014).

The ACA and Medicare

The ACA also impacts coverage for the majority of Medicare clients in a few ways. First, the health care law lessened the many employment disincentives attached to SSDI eligibility. Its enactment provided Medicare recipients with another avenue for securing comparable health coverage and supports outside of Social Security, thereby delinking medical care from employment. Secondly, some experts have suggested that the 24-month waiting period issue has ended with the passage of the ACA. Due to the short lifespan of healthcare reform, there is no published literature substantiating this belief. Therefore, the National Council on Disability and two advocacy organizations were contacted for further details.

Currently crafting a formal statement on this subject, the NCD stated that the ACA "might alleviate the issue for some," but it still posed a very serious problem to many SSDI participants. While they agreed that healthcare was available in all states through the marketplace, it presents a cost issue due to the premiums not required under Medicare. The NCD expert continued, explaining that many SSDI beneficiaries do not qualify for subsidies and others fall in the "gap". Additionally, this individual cautioned that a July 22, 2014 U.S. Circuit Court decision in Halbig v. Burwell ruled that under Section 1311 of the ACA, subsidies are available only for exchanges instituted by a state; therefore, federal marketplace subsidies were ruled as disallowed. Because 34 states did not establish a state exchange, their SSDI residents will not qualify for financial assistance (K. Borowicz, personal communication, August 7, 2014). An LA Times op-ed commented on this subsidy situation: "…if Hobby Lobby will create complications for Obamacare, Hlbig vs. Burwell could trigger a full cardiac arrest" (Turley, 2014).

Policy experts at the American Association of People with Disabilities (AAPD) agreed that the ACA can assist *some* SSDI beneficiaries confronted with the 24-month waiting period, but most will be left vulnerable due to "affordability" obstacles and ultimately have to forego insurance while they wait (H. Claypool, personal communication, August 8, 2014). The Christopher and Dana Reeve Foundation sees the situation this way:

These new options under health reform are an imperfect solution to the problems created by the two-year waiting period…..[And] the Reeve Foundation will continue the important work of communicating the devastating impact that the Medicare Two-Year Waiting Period has on the lives of individuals living with disabilities, and the increased costs associated with forcing individuals to forgo necessary medical treatments while waiting for coverage under Medicare (Christopher & Dana Reeve Foundation, n.d.).

In is important to note that the current administration has already petitioned for a rehearing en banc on this three judge divided decision. If granted, the case would be

reheard by all 11 judges on the D.C. Circuit Court and potentially be reversed. Hours after the *Halbig v. Burwell* ruling, the 4th Circuit Court of Richmond issued a unanimous yet conflicting ruling on *King v. Burwell*, upholding the availability of ACA subsidies in both state and federal exchanges (McCloskey, 2014).

Chapter 3: Current Program Offerings: Work Incentives

In additional to providing much-needed health care to SSDI and SSI participants, SSA encourages career advancement through a wide variety of employment supports. Many program enrollees desire to work; in fact, "40 percent of working-age disability beneficiaries report having an employment goal" (Schimmel, O'Day, & Roche, 2012, p. 1). Yet, these work-oriented participants face a number of barriers to do so, many of which are unrelated to their occupational capabilities. They fear employment disincentives inherent in the program structure which can precipitate the loss of disability benefits at even modest earning levels. SSI and SSDI work stipulations can threaten a participant's healthcare, force sudden loss of cash benefits, or make it impossible to accumulate financial resources helpful to moving toward self-sufficiency. Thus, few SSI/SSDI participants ever leave the rolls to return to employment.

"Well aware of the enormity and seeming intractability of this problem" and in an effort to dismantle some of these hurdles, the SSA and the federal government have implemented a growing number of interventions and other supports aimed at reducing the risks and costs associated with returning to work. Some of the most commonly used provisions involve retaining healthcare coverage, allowing a trial work period, temporarily permitting resource exclusions, and granting deductions for disability related work expenses (NCD, 2005, p. 9-10). These efforts reflect an overall policy objective to integrate people with disabilities into all aspects of society, assist these individuals in becoming self-sufficient, and fulfill a "desire by policymakers to stem the large caseload increase in programs that provide cash supports to people with disabilities" (Wittenburg, Mann, & Thompkins, 2013).

One rationale for initiating this expansive network of work supports is that "even a small increase in exit rates from SSDI and SSI could result in large programmatic savings. If only an additional one-half of one percent of the current…recipients were to cease receiving benefits as a result of employment, the savings to the Social Security Trust Funds and to the Treasury in cash assistance would total $3,500,000,000 over the

worklife [sic] of such individuals." This far exceeds the cost of providing these services (Wittenburg, Mann, & Thompkins, 2013).

To raise beneficiaries' awareness and to promote these programs, in 2013 SSA established the Office of Research, Demonstrations, and Employment Support (ORDES) to manage these return-to-work initiatives. Additionally, SSA created the Red Book intended to assist clients in navigating the work support system and the breaking down of employment barriers. The Red Book is a general reference source that provides a wealth of information regarding work incentives. This volume covers material intended to assist beneficiaries with entering, re-entering, and remaining in the labor force all the while protecting a participant's eligibility for cash benefits and health insurance. The agency opens its 2014 version by declaring that one of its "highest priorities is to support the efforts of disabled beneficiaries who want to work by developing policies and services to help them reach their employment goal." They further stated "Congress intended the employment support provisions to provide…the assistance need[ed] to move from benefit dependency to independence. (SSA, 2014, n.p.)

Below appears a listing of work incentives as they appear in the 2014 Redbook.

WORK INCENTIVES AVAILABLE TO BOTH SSDI AND SSI PARTICIPANTS

Ticket to Work (TTW)

The Ticket to Work Program is an innovative approach for both SSI and SSDI recipients who wish to pursue competitive employment. Once an individual enrolls in cash benefits, he or she is automatically eligible for TTW's services. TTW's operates through their "Employment Networks" (ENs): private agencies, vocational rehabilitation services (VR), or government entities. These partners with SSA to provide employment support to beneficiaries with disabilities at no cost. ENs enable TTW participants to access an array of services that are designed to assist them in securing or retaining career opportunities, all while keeping their health coverage (SSA, 2014). Contrary to common belief, there are no caps on annual enrollment.

Impairment Related Work Expenses (IRWE)

One of a number of income sheltering mechanisms offered by the SSA, IRWE disregards expenses related to a person's disability when determining a person's monthly SGA. Qualifying deducts must be directly related to the specific impairment, are out-of-pocket expenses covered by the individual personally, and a cost not reimbursed by Medicaid, Medicare, or a private insurance carrier. Items typically falling in this category include mobility aides, certain transportation costs and specialized work-related equipment. An individual only qualifies for this credit in months they are employed (SSA, 2014).

WORK INCENTIVES FOR SSDI PARTICIPANTS ONLY

Trial Work Period (TWP)

A Trial Work Period (TWP) allows individuals to test their employment capacity for a period of nine months. During this time, recipients continue to receive their full monthly benefits, with no fear of exceed SGA. This permits them to earn an unlimited amount. The TWP does not have to occur consecutively. However, the accumulated 9 months must fall within a rolling 60-month timeframe (HUD, 2008).

Extended Period of Eligibility (EPE)

The Extended Period of Eligibility (EPE) follows the TWP and lasts for 36 months. In this period, a recipient receives benefits only in months wages fall below SGA (HUD, 2008), but not in months when earnings exceed SGA. Once the EPE has concluded, benefits are terminated indefinitely if a recipient's wages surpass SGA. However, it is possible to re-establish benefits should employment discontinue within five years of EPE completion (SSA, 2014).

Continuation of Medicare Coverage

Once a beneficiary gains full-time employment, they are entitled to at least 93 consecutive months (approximately 7 years and 9 months) of Medicare, provided they completed TWP. This guarantees continued health insurance for this vulnerable population, regardless of earnings (SSA, 2014).

Unincurred Business Expense

For those pursuing self-employment, SSA deducts any support donated by others from monthly SGA reviews. Deductions may be taken for items such as free rent, donated supplies or technology, or uncompensated help from friends or relatives. For an item or service to be considered an unincurred business expense, two criteria must be satisfied (SSA, 2014).

- The item or service must be a legitimate business expenditure
- The item must be purchased by someone other than the beneficiary.

WORK INCENTIVES FOR SSI PARTICIPANTS ONLY:

Plan to Achieve Self-Support (PASS)

SSA's PASS permits SSI recipients to develop and implement an individualized plan to accomplish a specified employment goal. Personal resources, such as SSI income and other assets, may be set aside and used to obtain the beneficiary's objective. These expenses are excluded when calculating SSI eligibility and monthly benefit levels. Items commonly counted under PASS relate to education, transportation, specialized equipment, or resources needed to start a personal business (SSA, 2014).

Earned Income Exclusion:

An Earned Income Exclusion is a three-step approach to calculating a SSI recipient's eligibly and monthly allotment payment:

- SSA disregards the initial $65 earned.
- Half of any remaining wages are automatically discounted.
- A $20 general income exclusion is applied (SSA, 2014).

Student Earned Income Exclusion (SEIE)

SEIE is intended for recipients under the of age 22 who are actively pursuing education. Here, a specified portion of monthly earnings is excluded from income for purposes of determining eligibility and benefits. Deductions can occur monthly, until yearly exclusions total $7,060 (SSA, 2014).

Blind Work Expenses (BWE)

For those facing visual challenges, SSA permits earned income connected to employment-related expenditures to be sheltered from monthly SSI determinations. Examples of qualifying expenses include attendant care services, visual and sensory aids, transportation costs, meals consumed during work hours, income tax payments, or guide dog expenses (SSA, 2014).

Property Essential to Self-Support (PESS)

Here, the value of any personal property deemed necessary for job-related activities is not considered in SSI determinations. Property intended for a trade or business, such as inventory or goods, or personal property used for work are counted. However, liquid resources (stocks, bonds, or notes) do not fall under PESS, except in the case they are an essential component of the specific business (SSA, 2014).

Special SSI Payments for People Who Work - Section 1619 (a)

This section of the Social Security law allows recipients to remain on the SSI rolls even when their total income equals (or exceeds) SGA. All that is required to receive this special consideration is to accurately report work activity (SSA, 2014).

Medicaid While Working - Section 1619 (b):

Recognizing the importance of Medicaid for disabled workers, SSA created Section 1619 (b), permitting health coverage to continue even when wages exceed the SSI threshold. To receive benefits under this program, a person must qualify as disabled and demonstrate that their gross earned income is insufficient to replace SSI, Medicaid, and any publicly funded attendant care (SSA, 2014).

Special Benefits If You Are Eligible Under Section 1619 and Enter a Medical Facility:

For those whose condition requires periodic hospitalization in a Medicaid facility or a psychiatric ward, SSA permits their cash benefits to continue for up to 60 days. This is a departure from the rule that restricts SSI monthly payments to be no greater than $30 for those under custodial care. For this provision to apply, the facility must agree to allow recipients to retain their monthly payment while in the facility (SSA, 2014).

Expedited Reinstatement (EXR):

EXR acts as a safety net for people who successfully return to work and therefore no longer receive entitlements. An individual who discontinues employment within five years after benefits stop may have payments reinstated immediately via an EXR request. The EXR provision also allows one to receive up to 6 months of temporary cash benefits

while a medical review is executed to re-assess eligibility. Medicaid and/or Medicare may also be available during this provisional benefit period (SSA, 2014).

ANALYSIS:

It has proven to be a significant challenge to develop successful work interventions for people with disabilities under SSA's present definition of disability and the many disincentives inherent to the federal disability programs.

One would think the above wide array of SSA-sponsored employment supports might narrow the employment gap between SSI/SSDI clients and their non-disabled peers. Yet, Americans with disabilities remain underemployed with only 18.7 percent of this population participating in the workforce, in contrast to 68.3 percent of people without disabilities (Rosen, 2014). Even more discouraging after several decades of these work incentives were results of a study conducted by the Current Population Survey (CPS). In 1981, CPS found that 7.3 percent of the U. S. working population suffered from a health condition that negatively impacted their employment prospects. Still approximately 35 percent of these individuals were employed while 32.6 percent reported relying on federal disability benefits. Almost thirty years later and in the face of much effort by the SSA, the CPS's 2010 version reveals the share of individuals reporting a work- limiting impairment was nearly identical (7.8 percent). Yet, percentage of those employed was then 22.6 percent and those relying on public monies had risen to 51.4 percent (Burkhauser & Daly, 2011).

Despite major investments and numerous initiatives designed to assimilate more SSI and SSDI participants back into the labor force, these efforts have significantly underperformed and SSI and SSDI beneficiaries continue to stay on the disability rolls. Further, SSA work incentive programs remain chiefly underutilized. In fact, under five percent of disabled participants take advantage of the work incentives for which they are eligible (SOR, 2012). In illustration, as of April 2012, 13.2 million federal disability enrollees qualified for work supports through the Ticket to Work initiatives. Yet only

approximately two percent or 290,000 beneficiaries capitalized on these opportunities (CBO, 2012).

The major reasons cited for the underutilization of these work incentives were: 1) beneficiaries were unaware that the work incentives existed or failed to understand how they impacted benefits 2) those who were aware of the incentives found the programs to be convoluted and confusing (NCD, 2005, p. 10-11). 3) work incentives were not available until after beneficiaries had spent a substantial amount of time away from employment and after a lengthy determination process 5) supports are administered by fragmented federal, state, and sometimes local agencies which beneficiaries did not understand 6) the strong disincentive pull of the SSI and SSDI program structures.

The disappointing outcomes of these work support programs have prompted consideration of new proposals which would support employment for people with disabilities *before* they exited the labor force.

Still, the question remains: "How can policymakers boost employment for people with disabilities …. and what services are most effective in the effort to help them find and keep jobs?" (Saroglia, 2009, p. 5).

Chapter 4: The Issue of Growth in the Federal Disability Programs

What has propelled the growth of disability programs? Was this growth anticipated? Will these factors be ongoing drivers of growth or are they one-time events that have run their course? These questions reveal sharp divides among government agencies, academic researchers, public policy experts and advocates for stakeholders (Daly, et al., 2013). In an effort to foster understanding of the issue, it is imperative to open the discussion to all of these entities.

EXPERT PERSPECTIVES ON THE DRIVERS OF SSDI GROWTH

Government Agencies

In March of 2013, when the chief actuary of the Social Security Administration, Stephen Goss, was testifying before the House of Representative's subcommittee on Social Security, he first reminded lawmakers that in 1994 the SSDI trust fund was just one year away from the depletion of its reserves. Shortly thereafter, the balance of program funds was restored by a reallocation of the payroll tax rate, designating a slightly increased portion to SDDI, without altering the overall tax rate. Further, Goss recalled that at that very time, two decades ago, the trustees of the SSA projected a return to the same point in 2016 (Goss, 2013).

Goss proceeded to argue before congressional members that the predominance of the increased SSDI enrollment over the last three decades reflected "predictable" and "transitory" factors. And he predicted the effect of these very factors would "diminish" and caseload expansion would "level off" (Goss, 2013, p. 6). Goss then explained these growth factors thusly:

- Baby boomers maturing into their high-disability years: as this cohort has grown older, disability cases have climbed substantially
- Swelling numbers of women participating in the labor force: in the 1970s and 1980s, women first joined the workforce in huge numbers and remained; they subsequently qualified for SSDI benefits.

- The 2003 raising of the Social Security full retirement age from 65-66: when disabled workers reach full retirement age, they begin receiving Social Security benefits rather than SSDI. The shift in retirement age postponed those conversions.
- A significant increase in the total U.S. population: between 1980 and 2010, the number of Americans escalated by over 70 million, creating many more potential SSDI claimants (Goss, 2013).

Substantiating Goss's assertions were economists David Pattison and Hilary Waldron from the Office of Economic Analysis and Comparative Studies for the SSA. In a separate 2013 report based on a solid but complex analysis, they succinctly proclaim that demographic factors "explain 90 percent of the growth" over the past three decades and "94 percent of the growth in the last 18-year subperiod" (Pattison and Waldon, 2013, p. 41).

Echoing some of Gross' sentiments while responding to media coverage on the growth, eight former commissioners of the Social Security Administration penned an open letter in early April 2013. Citing their "unique insight", they cautioned readers of "the dangers of mischaracterizing the disability programs via sensational, anecdote-based broadcast accounts." After acknowledging that the SSDI program has "grown significantly in the past 30 years", they reported that this growth "was predicted and is mostly the result of two factors: baby boomers entering their high disability years, and yu,.women entering the workforce in large numbers so that today many more persons are "insured" (Social Security News, 2013, n.p.)

The commissioners further advised that when reviewing the history of the SSDI, the actual story of insolvency is much less sensational. Since this legislation was enacted, Congress has transferred payroll tax funds between the OASI and SSDI trust funds a total of eleven times, and in both directions, to adjust funding for demographic shifts. "In 1994, the last time such reallocation occurred, SSA actuaries projected that similar

[transfer] action would next be required in 2016." The former commissioners state, [the actuaries] "were right on target." (Social Security News, 2013, n.p.).

Concluding their dispatch, they advise it is "vital" to consider all parts of this important program and "take a balanced careful look at how to preserve and strengthen" SSDI (Social Security News, 2013, n.p.).

The Federal Reserve Bank of San Francisco (FRBSF) also brought their explanation into the SSDI's growth discussion in their 2013 *FRBSF Economic Letter*. While these experts readily acknowledge that the aforementioned demographic trends played a role in the SSDI expansion, they also admit "our breakdown of SSDI caseload growth over the past three decades indicates that only between 43% and 56% of SSDI growth can be attributed to [demographic drivers]. This leaves a significant residual fraction between 44% and 57% that is unaccounted for". The analysts continue on to attribute the unassigned growth to "program operation" and the "value of benefits" (Daly, M. C., Lucking, B., & Schwabish, J. A. (2013, n.p.).

Initially, they point to the 1984 Disability Benefits Reform Act, which expanded the ways in which individuals could qualify for the SSDI program. This measure shifted the criteria for eligibility from a "list of specific impairments to a more general consideration of a person's medical condition and ability to work. The legislation allowed applicants to qualify for benefits on the basis of the combined effect of multiple medical conditions, each of which taken alone might not have met the criteria. It newly allowed symptoms of mental illness and pain to be considered in screening process. And, these modifications steered the composition of awards toward petitioners with low-mortality ailments" (Daly, et al., 2013, p. 4).

Concluding their letter, these government experts warn that the effects of these two factors may, at some point, increase rapidly and push SSDI participation beyond the SSA's projections (Daly, et al., 2013).

Rounding out the governmental stance on federal disability growth are perspectives from SSA's Administrative Law Judges (ALJs). As of July 2013, 838,000 persons had filed an appeal in the SSA disability adjudication process and were in line for a hearing (OIG/SSA, 2014). Most would wait a year of more. A number of these ALJs working for the agency are convinced that this bottleneck is contributing to the burgeoning disability rolls.

When individuals apply for the federal disability programs, their determination process originates with a local state agency which has been contracted by the SSA and is named Disability Determination Services (DDS). At this initial level, two-thirds of all applications are denied. After this refusal, a denied applicant may request a "reconsideration" which will also be deliberated by the DDS. If the applicant is declined an additional time, he or she may appeal the case to an ALJ. To enter into this hearing process is to endure a long delay. While much improved since 2007 when the wait for adjudication was 512 days, the wait in 2013 was still 375 days, slightly more than a year (Sklar, 2013, p. 2). But some claim it is worth it, for here the approval rate rises to 58 percent, up from one third (Dubin & Rains, 2012, p. 3). And more than a few of these judges are testifying this high approval rate is due to pressure on them to reduce the enormous backlog of cases.

At a June 2013 congressional hearing before the Committee on Oversight and Government Reform, several ALJs portrayed a hearing system "where there is little incentive to deny claims but lots of pressure to approve them." One current ALJ referred to this situation as "Paying down the backlog" (Ohlemacher, 2013) and another called it "Pay so they go away" (Swank, 2012, p. 178). A third judge advised that "it requires more documentation to deny a claim than to approve one" and it was just easier and faster to reduce the logjam by approving claims. Although none of the testifying judges asserted they had been "ordered to award claims, three said they had been pressured to decide cases without fully reviewing medical files" (Ohlemacher, 2013).

In a 2013 lawsuit filed against the SSA, the union representing these ALJs declared that in order to relieve the massive buildup of disability hearings, their members are mandated to rule on 500-700 cases a year. The union opines that this "illegal quota leads judges to sometimes award benefits they might otherwise deny just to keep up with the flow of cases." The judges state "the quality of their decisions has suffered" in this overwhelming caseload environment (Ohlemacher, 2013).

Critics of these assertions dismiss claims leveled by these disgruntled ALJs. They state that climbing disability enrollment is not a "function" of ALJ leniency because these judges' "decisions amount to a relatively small portion of disability awards, compromising fewer than 25% of total annual awards" (Dubin & Rains, 2012, p. 2).

Academic Researchers:

Economics professors David Autor of MIT and Mark Duggan from the University of Maryland have been sounding the alarm over the state of the SSDI program for more than a decade. And in sharp contrast to other experts, they opine that "the aging of the baby boom generation has contributed little to the rise of receipt of disability benefits" (Autor, D., & Duggan, M., 2006).

In their thesis "The Growth in the Social Security Disability Rolls: A Fiscal Crisis Unfolding," they espouse their belief that SSDI growth, rather than being temporal, will rise an additional 70 percent, and reach 6.5% of adults between the ages of 25 and 64 before finally stabilizing. The professors trace "the rapid expansion of the SSDI beneficiary population [to] three main causes:"

- First, the 1984 congressional reforms aimed at SSDI eligibility enabled workers with low mortality disorders such as back pain, mental illness and arthritis to more readily qualify for benefits. Thus, not only did the number of participants grow, but the average duration of disability tenure lengthened as well.

- Second, a rise in the after-tax SSDI income replacement rate -- the ratio of disability income to former labor earnings -- which strengthened the incentives for workers to seek benefits.
- Third, a rapid increase in female labor force participation expanded the pool of insured workers (Autor, D., & Duggan, M., 2006).

Similarly, American Enterprise Institute scholar and Cornell professor Richard Burkhauser dismisses the role of demographic factors, such as an aging workforce, in fueling the "pandemic" growth of SSDI. Instead, he advances the belief that the growth is "primarily the consequence of fundamental flaws in the SSDI program and its administration which have increasingly made it a long term unemployment program rather than the last resort transfer program" for disabled laborers (Burkhauser, R. V., & Daly, M., 2012, n.p.). In the media and his research, Burkhauser emphatically avows the loosening of program rules in the 1980s made it more difficult for gatekeepers to judge eligibility and greatly increased the likelihood that marginally impaired workers would receive benefits. Burkhauser asserts these program flaws become most evident during severe economic downturns but promises they remain long after economic recovery (Burkhauser, R. V., 2012).

Public Policy Experts:

Things look different to experts at The Center for Economic and Policy Research (CEPR), an organization "conducting both professional research and public education" and founded "to promote democratic debate on the most important economic and social issues that affect people's lives (Center for Economic Policy Research, 2013, n.p.). In 2013, compelled by its mission, CEPR felt it necessary to comment on a widely broadcast radio program, which mischaracterized the growth of the SSDI program and its participants.

The media piece claimed that SSDI had "become a de facto welfare program for people without a lot of education or job skills." It continued on to assert as a result of

liberalized eligibility standards, individuals "capable of working are opting for the disability rolls when confronted with employment challenges." These claims reverberated circulating political cries that Americans are "gaming the system" and the program was plagued with "widespread fraud" (Center for Economic Policy Research, 2013, n.p.).

CEPR countered these assertions which relied mainly on anecdotal evidence by stating, "It seems more than a bit of a reach to explain expanding disability rolls on some of the items covered in the [news program]…..There is a simple explanation [for the growth of SSDI] that "doesn't require examining the moral turpitude of the beneficiaries or evidence of corrupt or negligent [SSDI] administrators." CEPR stated that after accounting for projected increases due to demographic factors, "the explanation for this increase seems pretty clear…Fix the economy and you would remove much of the burden on the program" (Center for Economic Policy Research, 2013, n.p.). Clearly, CEPR feels it is the economy driving the growth of SSDI.

Lastly, Kathy A. Ruffing of the nonpartisan Center on Budget and Policy Priorities (CBPP) also shared her organization's views on the matter. Speaking before the Social Security Subcommittee of the House of Representatives in spring of 2013, the senior public policy expert advised that "contrary to the impressions conveyed by many recent critics, changes in the workforce explain most of the growth in the disability rolls." Several important factors have inflated the count of disabled workers substantially during the last few decades: the baby boomers, the influx of women into the workforce, and the change in the retirement age. She added that other factors, not fully understood, have boosted rates of receipt: economic downturns, program eligibility, and workplace factors. Ms. Ruffing concludes her testimony by insisting that eligibility criteria are "stringent" and that benefits are "modest." And there is little evidence that SSDI benefits are going to persons who could support themselves by working. New beneficiaries experience a drop in their standards of living since benefits are in the neighborhood of 55 percent of their former earnings (Ruffing, K. A., 2014).

Advocates for Stakeholders:

Countering critics of SSDI and rumors of its "out of control" growth, the Consortium for Citizens with Disabilities (CCD, 2013, n.p.) refutes claims of lax SSDI eligibility criteria and loose administrative standards by proclaiming that "the Social Security Act's disability standard is one of the strictest in the developed world. According to the Organization for Economic Co-operation and Development (OECD), the U.S. has the most restrictive and least generous disability benefit system of all OECD member countries, except for Korea." CCD also advises that "most applicants for Social Security disability benefits are denied. Fewer than four in ten are approved, even after all stages of appeal (CCD, 2013).

Just as vehemently, the Medicare Advocacy Organization recently published a public retort entitled "Setting the Record Straight: The Social Security Disability Program. The treatise's authors claim that exaggerated attacks and numerous demands for policy changes have come to overshadow "the real reasons for growth". While the group acknowledges that SSDI enrollment is growing, they state unequivocally the "demographic factors rather than program inefficiency and policy changes explain most of this growth" (CMA, para. 6, n.d.).

ANALYSIS:

There is no dispute that the Social Security disability programs have grown significantly since they were signed into law, as well as in recent years. And it is equally clear that there exists no consensus as to the causes of this growth.

In fact, professionals offer a full spectrum of explanations: demographic factors, the economy, program flaws, changes in eligibility criteria, increased value of benefits, Americans gaming the system, the bottleneck of ALJ hearings, and even a mention of fraud. Further, there is frequent and direct contradiction between experts: The SSA states demographic factors explain 90+ percent of the growth while the FRBSF counters that it accounts for around 43-56 percent. And academics dismiss the demographic explanation almost all together. As to the trend of this growth, one expert asserts it will

shortly be leveling off, another states it will rise another 70 percent before stabilizing. Finally, Burkhauser claims 1980s legislation begot lax eligibility; contrarily, the CCD insists that SSA's disability standard is one of the strictest in the developed world.

But this much is certain. This is not a runaway program that should be sensationalized with cries that costs are "out of control". Twenty years ago SSA actuaries precisely predicted that the SSDI trust fund would be exhausted in 2016. Further, the trajectory of growth has progressed exactly as the agency anticipated. None of this comes as a surprise. So, how do we explain all of this?

The Center of Budget and Policy Priorities (CBPP) weighs all of the above and offered their conclusion in a January 2014 brief "How Much of the Growth in Disability Insurance Stems from Demographic Changes?" Almost immediately, CBPP advises "there is no single correct answer" to their title query (Ruffing, 2014). The publication goes on to explain that the great differences in response to their question "largely reflect variations in the measure of growth that the studies use": growth in the number, rate of SSDI receipt, percentage of workers who receive benefits, or applications versus awards, etc. Also varying are the factors considered and the time period analyzed (Ruffing, 2014).

Some of the expert assertions can be verified, such as role of the economy as a driver of growth. Statistical analysis demonstrates that "while economic downturns tend to boost *applications*, research finds that they have a much smaller effect on *award* (Figure 2). Yet others, such as the stringency of the eligibility criteria, are difficult to quantify.

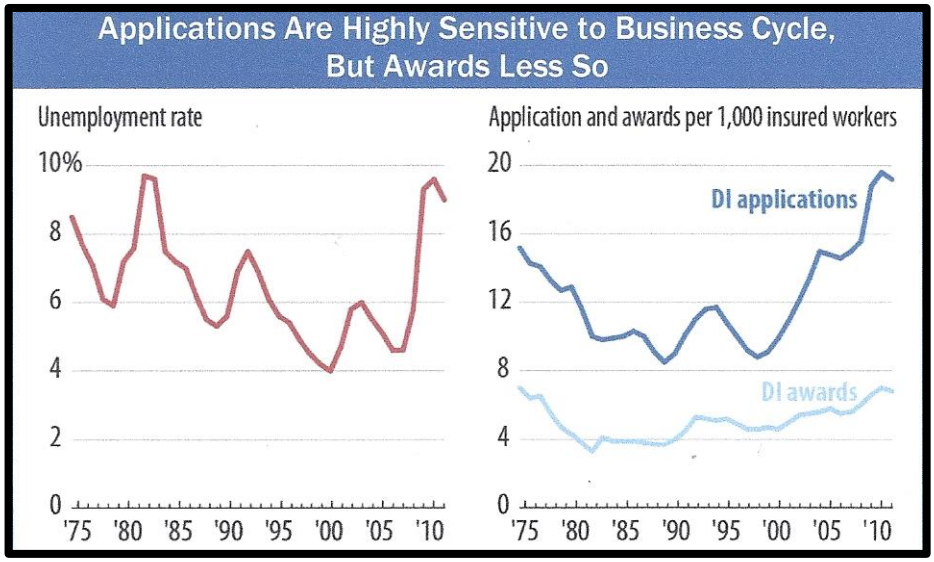

Figure 2. Applications are highly sensitive to business cycle, but awards less so. Reprinted from Center on Budget and Policy Priorities. K. A. Ruffing, 2013, Retrieved July 2, 2014, from http://www.cbpp.org/files/8-9-12ss.pdf.

But overall, with so little consensus, it would be foolhardy to respond to calls for systemic or fundamental change as advocated by some. In illustration, one public policy organization recently advocated immediate action, claiming that "SSDI has become financially unsustainable and economically damaging, and policy makers should pursue major spending cuts to the program. They should also explore the potential to transition responsibility for disability insurance from the government to the private sector" (DeHaven, 2013, n.p.)

As policymakers and experts work to more clearly pinpoint the drivers behind the growth of SSDI in order to craft feasible, long-term solutions, smaller yet effective reforms should be implemented.

EXPERT PERSPECTIVES ON THE DRIVERS OF SSI GROWTH

Since its launch in 1974, SSI has grown considerably in terms of enrollment and expenditures; however, its expansion is modest when compared to SSDI. (Figure 3)

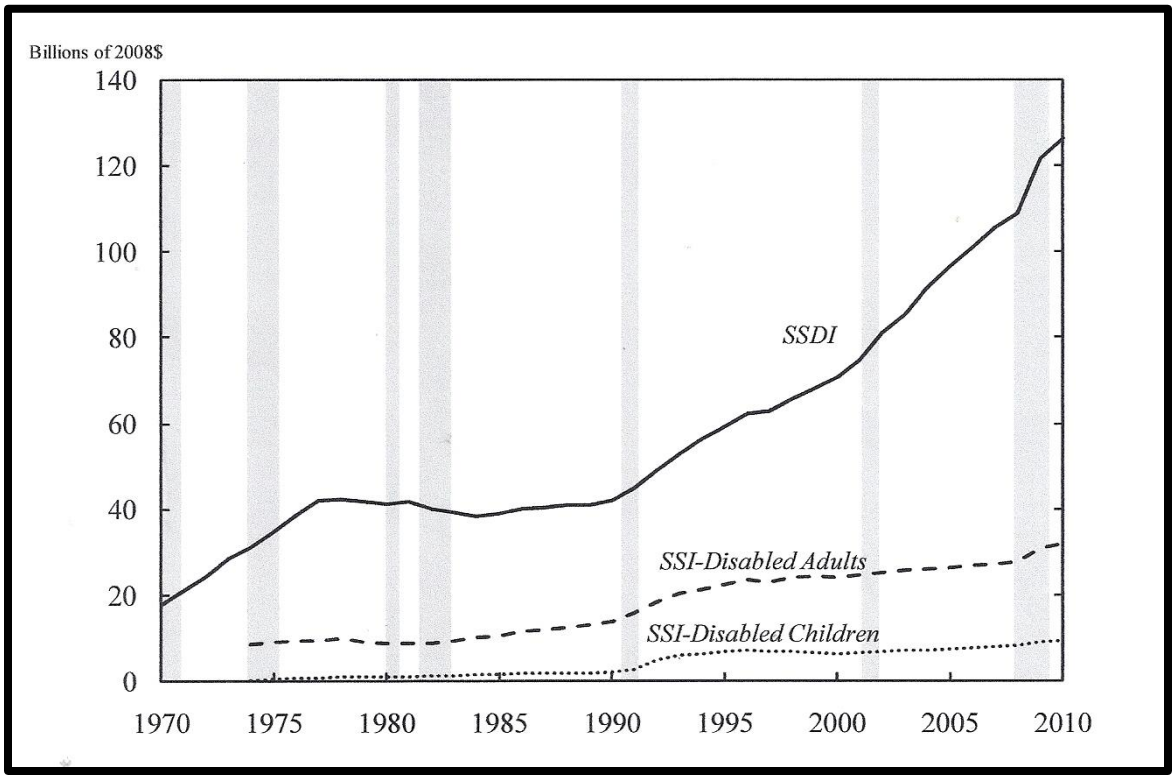

Figure 3: SSDI, SSI - Disabled Adults. and SSI – Disabled Children Program Costs over Time. Reprinted from The Declining Work and Welfare of People with Disabilities: What Went Wrong and a Strategy for Change (p. 2), by R. V. Burkhauser and M. C. Daly, 2011, Washington, D.C.: The AEI Press. Copyright 2011 by the American Enterprise Institute for Public Policy Research.
Note: Gray bars denote National Bureau of Economic Research (NBER) recessions
Source: Social Security Administration

payments averaging $507. Total benefit outlays during calendar year 2012 were $51.7 billion (SSA, 2013). In the last decade, program growth has merely kept pace with the rise in the U.S. population and the swell of poverty among children (Vallas & Alfano, 2012). Nonetheless, debate rages among various experts in the field regarding the program itself and its growth.

Government Agencies

According to SSA actuaries, since the inception of the program, the number of blind and disabled participants has marginally, but steadily expanded while elderly participation has declined. However, the 1990 *Sullivan v Zebley* decision spurred temporary but dramatic growth in the enrollment of children (Smith, 2013). The court held that the agency, when determining eligibility, must look beyond the current SSI listing of disorders and conditions and weigh the "functional impact of a child's impairment" as is the case with adults (Vallas & Alfano, 2012, n.p.). Responding to the resultant surge in enrollment, in 1996, Congress implemented reform which amended the 1990 definition of disability in children with one that was more restrictive. This legislation prompted a "small contraction" in program inflation, but modest growth began again in 2000 (Smith, 2013, p. 25). The Great Recession which commenced in late 2007 brought about a new uptick in participation.

In their 2013 *Annual Report of the Supplemental Security Income Program*, SSA experts forecasted that over the next few years, the number of program participants will grow slightly faster than the U.S. population, reflecting "the still-elevated unemployment rates… from the recent economic downturn." The program will then revert to modest growth for the balance of the next quarter of a century. Expressed another way, analysts estimate that relative to the total U. S. population, enrollment will rise slightly from 2.51 percent in 2012 to 2.53 in the next several years. Subsequently, it will slowly and steadily decline to 2.42 percent of the population by 2037, expanding slower than the overall U.S. population (SSA, 2013, n. p.).

In 2012, responding to alarmist cries of program growth, the Senate Budget Committee requested that the CBO prepare an overview document detailing the SSI program.

CBO found that in the early 1990s participation in SSI increased markedly, "in part because of changes in eligibility," (CBO, 2012, p. 1) but also because the SSA accelerated public education regarding the program (CBO, 2012, p. 4). CBO experts

state that participation rose again between 2006 and 2011, primarily due to the economic downturn. They believe that escalating poverty, also attributed to the recession, appears to have instigated growth in the number of child SSI recipients. But CBO anticipates that "the share of children receiving payments for the first time will decline slightly over the next few years as poverty rates fall because of an improving economy" (CBO, 2012, pp. 1-5).

CBO experts continue on to predict that in the coming years, the total number of SSI beneficiaries will decline slightly as a share of population. They also project that total outlays for SSI will decline slightly relative to total GDP over the next decade. Yet overall, the count of SSI beneficiaries has climbed slightly faster than the general population growth since the 1990s (CBO, 2012).

Academic Researchers

Richard Burkhauser disagrees with governmental assessment of the pace of SSI growth. The Cornell professor of policy analysis and American Enterprise Institute scholar purports that SSI has grown very rapidly over the last 25 years, especially as relative to the U.S. population. And to him, the SSI program "exemplifies America's flawed approach to social welfare policy" (Burkhauser, 2012, p. 5). Burkhauser dismisses the assertion advanced by other experts that the expansion of SSI is partly the inevitable result of the growing poverty of families with children and the expanded understanding of children's mental health issues. Rather he emphatically argues that *all* of SSI's "enormous" growth over the past quarter of a century is the consequence of poor policy decisions (Burkhauser, 2011, p. 4)

First, Burkhauser, like many other analysts, points out that enrollment leaped following the 1990 Supreme Court decision which broadened participation by allowing "function" to be an eligibility consideration. The professor bemoans the resultant program growth which he attributes to the moving away from "medically measurable qualifications" of children's mental health such as mental retardation, toward the more

subjective and difficult to evaluate "other mental conditions" which includes autism, ADHD, and learning disabilities. Burkhauser believes this new subjectivity, implemented by lax gatekeepers of the program, is, in fact, a major culprit of SSI growth (Burkhauser, 2012, p. 6). To bolster his assertion, Burkhauser correctly, but misleadingly, reports these "other mental conditions" which measured five percent in 1983 had skyrocketed to 55 percent by 2010 (Burkhauser, 2012, p. 6).

Secondly, Burkhauser states that the above eligibility subjectivity combined with the general welfare reform of 1996 has also had a major hand in SSI growth. He opines that today's SSI program should more accurately be dubbed "Aid to Families with Disabled Children" due to the fact that it does not directly provide services to children with disabilities, nor tie benefits to the purchase of services for the disabled child (Burkhauser, 2011, p. 4). He shores up his claim by noting that SSI cash benefits surpass those of TANF, are longer lasting, and have no work requirement attached. In fact, under the SSI-disabled children program, benefits can continue until the child turns eighteen years of age, and the parent is never expected to seek employment (Burkhauser, 2011, p. 5). Burkhauser believes these features increase the interest of able-bodied single mothers, whose offspring have medical conditions, in applying. And he claims, in fact, they do, capitalizing on the lax and subjective eligibility requirements (Burkhauser, 2012, p. 6). Unfortunately, Burkhauser fails to mention that the program's optional parental work requirement allows for a parent to meet the intense daily care demands of a disabled child, while the ongoing enrollment attempts to accommodate the sometimes enduring health challenges faced by youngsters on SSI.

Burkhauser next argues that states have an incentive to transfer TANF families to the SSI-disabled program in order to move the financial burden to the federal government, thereby reducing costs states would absorb in trying to encourage parental employment.

Burkhauser climaxes his treatise by stating that "the most shocking aspect of this program's growth is its failure to transition" this burgeoning share of children, who with appropriate education and training, could seek employment as adults and "age off the SSI program" (Burkhauser, 2012, n.p.).

In a single statement, Burkhauser encapsulates his explanation for SSI growth by asserting "since past policy changes are the cause, future policy changes can be the solution" (Burkhauser & Daly, 2011, p. 3).

Holding a more favorable view of the SSI program is Dr. Lucie Schmidt. The economics professor at Williams College and scholar for The Federal Reserve Bank of Boston (FRBB), opines that SSI "has become one of the most important means-tested cash aid programs in the United States" (Schmidt, 2012, p. 2). Nonetheless, she notes that the number of adult SSI recipients has grown 89 percent and enrollment of children has quadrupled over a period of three decades (Schmidt, 2012).

Schmidt advises that, "existing research tells us little about the determinants of SSI caseloads, which vary dramatically both across states and over time" (Schmidt, 2012, p. 2). Her research offers clear evidence that SSI participation and growth over the last thirty years has varied widely from state-to-state, as well as among states in the same region. She offers, for example, that "while caseloads rose in West Virginia over the entire 1980-2010 period, they peaked in Mississippi in the mid-1990s and have fallen in most of the subsequent years." And "New England states, Massachusetts and Rhode Island had similar rates of SSI participation in 1980, but diverged in the mid-1990s" (Schmidt, 2012, p. 5). Additionally, her analysis found that the chronology and pattern of SSI growth by state differs widely. She attributed all of these variations in state enrollment to dissimilarities in the health of a state's population, differences in the economic climate prevailing in states, disparities in the availability and liberality of other programs that can serve as a substitute for SSI, and deviations in the stringency of program criteria as executed by SSI state administrators (Schmidt, 2012).

Dr. Schmidt concludes that there is "preliminary evidence" that economic conditions clearly plays a role in SSI enrollment but the relationship between SSI caseload and unemployment remains perplexing and demands further study to "fully understand this relationship" (Schmidt, 2012, p. 18). She also notes that a high percentage of births outside of marriage are positively correlated with increased SSI enrollment. And like Burkhauser, Schmidt feels that SSI "plays the role of an alternative safety net in the post-welfare reform era" (Schmidt, 2012, p. 18). However, unlike Burkhauser, this researcher applauds the presence of financial support for these low-income households which include persons with disabilities.

Public Policy Experts

Countering the assertion that SSI has been growing rapidly, the non-partisan public policy analysts at CBPP calculate that "until the deep recession caused a modest uptick [in 2008], SSI participation had generally been flat or falling as a share of the population since at least the mid-1990s" (Ruffing, 2014, p. 3)

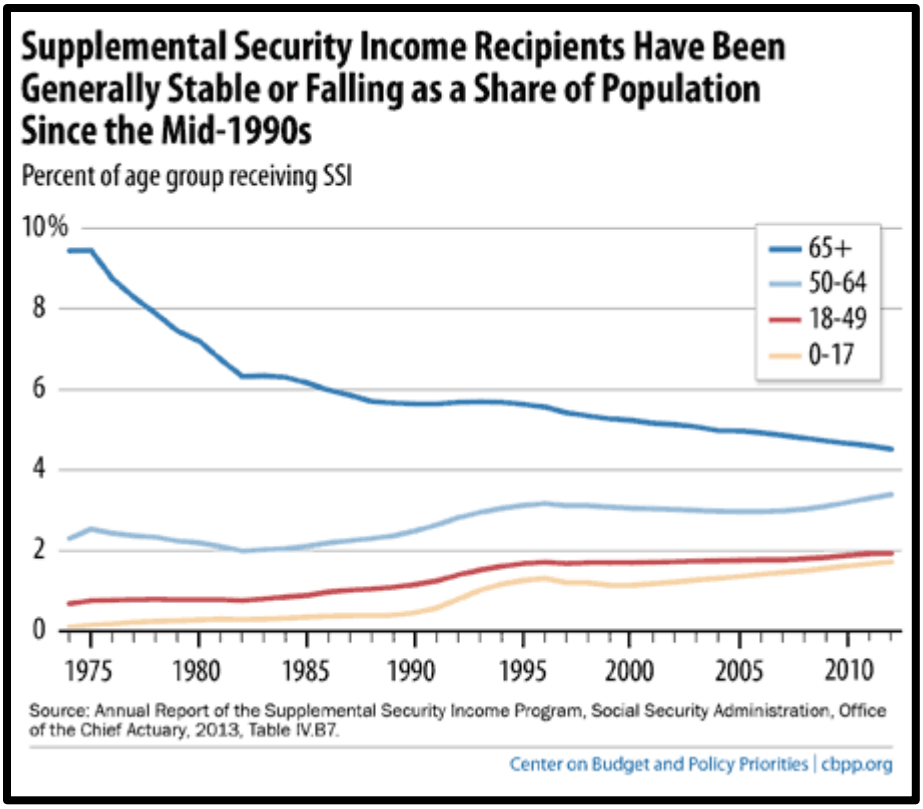

Figure 4. Supplemental Security Income recipients have been generally stable or falling as a share of population since the mid-1990s. Reprinted from Center on Budget and Public Priorities, by K. A. Ruffing, 2012. Retrieved July 8, 2014 from http://www.cbpp.org/cms/?fa=view&id=3367

Contributing to the somewhat stable rate of enrollment spanning almost three decades is the fact that the growing number of child recipients has been countered by the declining number of elderly participants (Figure 4). CBPP analysts expound that the increase in child beneficiaries, as sensationalized in the media, has been precipitated by a rising rate of disability among children. Incidence of disability of those 0-17 years has "inched up very gradually for the last decade, probably due to advances in detection and diagnosis of certain disabling conditions" (Ruffing & Pavetti, 2012, p. 2). And concurring with other experts, they acknowledge the program holds abysmal exit rates; once enrolled as children, two-thirds continue directly onto the adult rolls. Also prompting an upturn in enrollment of children has been the rising rate of childhood poverty, provoked by the "prolonged economic downturn."

CBPP concludes their report by acknowledging there exists one growth-related component of the SSI program that can, and should be, legitimately censured. SSA has a "powerful tool at its disposal" to ascertain that only individuals who remain severely disabled are allowed to stay on the program: the continuing disability review (CDR) (Ruffing & Pavetti, 2012, p. 4). The agency is mandated to execute these reassessments for the majority of its cases at a minimum of every three years. Currently, SSA does not fulfill this duty as it should. Resultantly, enrollment rolls can be inflated and incur unnecessary program costs (Ruffing & Pavetti, 2012).

Another public policy organization, Kaiser Foundation News, waded into the SSI waters for a better understanding of the growth of SSI and the factors prompting its expansion. Health analyst Jenny Gold investigated the children's portion of SSI, explaining that it is "rapidly expanding, with the biggest increase among kids with mental, behavioral and learning disorders, including ADHA, speech delays, autism, and bipolar disorder" (Gold, 2011, n.p.). Kaiser's examination was prompted by a newspaper series entitled "The Other Welfare" which featured alarming implications regarding ballooning participation and some of the children enrolled in SSI.

Performing their own examination, Kaiser reported that heightened use of the SSI program resulted from a "national increase in child poverty" as well as broader access to health care for kids. The latter brings earlier diagnosis and more frequent and accurate discovery of disability (Gold, 2011, n.p.).

Kaiser also explains that children "who were once characterized as mentally retarded may now be diagnosed as having autism or another mental disability. Overall, the percentage of kids on the program with any form of mental disability, including retardation has remained largely stable since the early 1990s" (Gold, 2011, n.p.). While this finding does not change overall enrollment numbers, it does answer critics who claim that SSI rolls are packed with children who secured benefits under questionable and very subjective criteria.

Advocates for Stakeholders

Highly partisan and advocate for downsizing the U.S. government, Tad DeHaven of the Cato Institute, provocatively proclaims that SSI "has become another bloated federal welfare program that encourages government dependency and discourages individual initiative," all at the expense of taxpayers (DeHaven, 2013, n.p.). He cites substantial increases in participation between 1990 and 2013, over which time enrollment rose from 4.8 to 8.3 million. DeHaven blames this inflated participation on liberalized policies which loosened eligibility criteria and resulted in "a complex, subjective, and outdated determination process….[which] has created a breeding ground for awarding and continuing benefits for people who shouldn't be on the disability rolls" (DeHaven, 2013, n.p.).

Especially alarming to DeHaven is the swelling enrollment of children "who are qualifying for SSI on the basis of a mental or behavioral disability" (DeHaven, 2013, n.p.). He explains that the program's original objective was to assist children with "clear disabilities" such as Down syndrome, mental retardation, and cerebral palsy. He is troubled that in the wake of the *Sullivan v Zelbey* decision that SSI has become overrun with persons having with a "claimed" mental or behavioral challenge. Further, DeHaven contends these children will become adults who do not actually possess a permanent disability but instead are individuals lured into lifelong government reliance" (DeHaven, 2013, n.p.).

Supporting his claims, the author of this Cato report refers to a highly publicized and controversial 2010 *Boston Globe* series of reports. These journalistic essays highlighted SSI participation by children enrolled under "questionable circumstances." The *Globe* articles purports that many low-income parents desire to have a child who can "pull a check" from the federal government. The newspaper supported these claims with tales of parents attempting to secure their child psychotropic drugs, which they believe increase the chances their youngsters would qualify for SSI benefits. DeHaven

comments “the child qualifies for the check but the parent gets the money” (DeHaven, 2013, n.p.).

Echoing a concern of other SSI experts, DeHaven notes the lack of Continuing Disability Reviews (CDRs) being conducted on children. The essay claims that number of CDRs dropped 70 percent from 2000 to 2011 and that there are currently 435,000 children on SSI for a mental disability who are overdue for a CDR (DeHaven, 2013).

DeHaven blames all SSI growth on a federal government which “seems incapable of running welfare programs in a frugal manner with due regard to taxpayer’s interests. The dismal low rate of disability reviews is clear evidence that the federal government is simply not doing its job to protect the public purse by making sure that only the truly needy are collecting benefits.” He then demands that this “troubled experiment be ended” and the “responsibility for caring for the needs of the indigent should rest with private charities, churches, and other voluntary organizations” (DeHaven, 2013, n.p.).

ANALYSIS

The above review on SSI growth offers the only unanimous agreement among expects concerning either federal disability program.

All SSI-related professionals agreed that the increased enrollment of children has spurred a rise in this program’s participation. Beyond that consensus, as was the case with SSDI, perspectives on prompters of growth varied widely. Explanations more than equaled the number of experts surveyed and included: changes in eligibility, the economy, increased public awareness of the program, escalating poverty among children, poor policy decisions, lax program gatekeepers, low exit rates, variances from locale to locale, failure to perform CDRs, intentional cost shifting from states to federal budgets, fraudulent claims, general welfare reform, and an overall broader access to and understanding of healthcare for children. Depictions of the rate of growth fluctuated between “modest and flat, as a share of the population” to “growing very rapidly,

especially as relative to the U.S. population." Startling, both of these last descriptions were regarding the same period of time.

A majority of those polled agreed that the 1990s change of eligibility criteria altered participation among children with mental health conditions. Burkhauser and others charge this policy change brought subjectivity to enrollment and as a result the program is now overrun with children having "questionable" and non-quantifiable mental conditions. Others considered the modification simply a broader and more modern understanding of mental health in children. Elaine Alfano, deputy policy director for Bazelon Center for Mental Health Law in Washington, D.C., explains that there has been no great recent influx of children with mental disabilities into the program – the percentage of SSI children with mental conditions has, for decades, held constant. Those with mental impairments have long formed the majority of child SSI recipients and the breakdown between physical and mental impairments has remained steady over the last two decades. While Alfano agrees there has been a 29.3 percent drop in the segment of children with "mental retardation," from 1991 to 2010, there has been a corresponding 30 percent uptick in the portion of children receiving SSI for other mental impairments such as ADHD, learning disabilities, or communication challenges. "Children who once might have been diagnosed with mental retardation are now more accurately diagnosed with autism, communication disorders, or learning disabilities" (Vallas & Alfano, 2012, p. 67-68). This strong shift is not unique to SSI applicants but is reflective of the contemporary understanding of pediatric mental health. Additionally, sixteen of America's largest mental health advocacy groups, including the American Psychiatric Association, the American Academy of Pediatrics, and Children and Adults with Attention Deficit/Hyperactivity Disorder have launched a campaign to explain the "truth" about the growth in SSI among children (Gold, 2011).

While nearly all experts agree with Burkhauser that the majority of enrolled children continue directly onto SSI adult disability rolls, they object to his assertion that this is "shocking" and due to a program failure to provide education and training. Most

understand that SSI eligibility requires a severe impairment and therefore outcomes, such as economic independence, is not always a reasonable expectation. CBPP's senior policy advisor, Kathy Ruffing, presents an alternative perspective on this subject. "Because SSI participants … have severe disabilities, it is no surprise that relatively few of them work, even though program rules allow and encourage them to do so" (Ruffing, 2014, p. 4). She goes on to elaborate "Severe disability, exacerbated by poverty, hampers adult outcomes" (Ruffing, 2014, p. 4). Ruffing then refers to academic research which presents new evidence that significant childhood physical and mental health issues have large impacts on four key areas of "socioeconomic status as an adult: education, weeks worked per year, individual earnings, and family income." She then scolds the detractors, "It is not appropriate [for policy analysts] to compare statistics" for graduation rates and job-holding for those who receive SSI and those who don't. The two groups differ in fundamental ways". Similarly, she continues, there is no basis for blaming challenges in adulthood on receipt of benefits as a child. In fact, some studies suggest that "childhood SSI benefits improve adult outcomes" (Ruffing, 2014, n.p.).

Lastly, there is a good bit of agreement and concern from both sides that the failure to regularly execute Continuing Disability Reviews (CDRs) is unnecessarily inflating SSI enrollment. The agency attributes this breach of policy to Congressional funding cuts. Between 2004-2008 there was a 65 percent decline in CDRs (Pulcini, Perrin, Sargent, Shui & Kuhlthau, n.d.). And, a recent SSA in-house study revealed that for every dollar spent on a CDR, approximately $10 in benefit and healthcare costs can be saved by SSA (Ruffing & Pavetti, 2012). The professionals agree that this review process must be regularly executed to control program growth.

Chapter 5: Structural Issues Within the U.S. Disability System

Outdated paradigm

Over the last quarter of a century medical, societal, economic, built environment, legal, and technological advances have multiplied opportunities for persons with disabilities in terms of inclusion, increased independence and participation in the workforce. Instances of these changes would be improved wheelchair designs and curb cuts, allowing enhanced independence for physically challenged persons or the economic shift toward knowledge-based employment, offering greater workforce participation for some persons confronting physical limitations. Despite these many modern advances, analysis of the present federal disability system, in particular SSI and SSDI, clearly demonstrates that the structure of these programs have not "evolved with these larger societal changes." Therefore, the disability system is "poorly positioned to provide meaningful and timely support for persons with disabilities" (GAO, 2007, p. 1).

The framework of today's disability policy was built upon programs originating during the Eisenhower, Kennedy, Johnson, and Nixon administrations. These programs were a shift from the previous model of charity and segregation to one of paternalism and dependency, with an emphasis on medical oversight (Stapleton & Livermore, 2011, p. 3). This 1960-70s protective model regarded people with disabilities as "in need of fixing," "defective," and requiring caretaking (Blanck, Clay, Schmeling, Morris, & Ritchie, 2002, p. 662). It was on this paradigm that the U.S. government devised current program strategies to meet the needs of disabled people. The resultant system is the present programs that allot far greater expenditures to a paternal safety net than to programs directly advancing goals of self-sufficiency and independence (Stapleton & Livermore, 2011, p. 3). And today this left-over 20th century disability policy is "failing many of those it was designed to help" (Mann & Stapleton, 2012, p. 1).

Within the U.S. disability system the dominant players are SSI and SSDI. Because the reach of these programs is so broad, their programmatic features dictate

overall federal disability policy. Their eligibility requirements, program rules, and emphasis on cash transfers sends a tacit message to program participants.

The primary eligibility criterion for SSI or SSDI focuses on an almost complete inability to work, except in the case of children. It demands extensive verification of a "medical condition that will result in death or has lasted or can be expected to last for at least 12 months and which results in an inability to work at a substantial level" (NCD, 2005, p. 78). This admissibility mindset also "fails to recognize that many people whose impairments limit their capacity can still make significant contributions to their own financial support. By making complete inability to work a criterion for support, these programs create work disincentives, erode work capacity, foster long-term dependence, and increase poverty" (Mann & Stapleton, 2012, p. 1). Thus, this eligibility model builds a very fundamental flaw into America's disability system: beneficiaries must prove they are unable to perform gainful activity and program rules thwarts return-to-employment efforts, all the while administrators encourage beneficiaries to return to work (Saroglia, 2009, p. 7). This very contradictory eligibility framework "has been in place with little change since SSDI's inception in 1956" (Livermore, Wittenburg, & Neumark, 2014, p. 4).

This "unable-to-work"/caretaker emphasis in the SSI and SSDI programs is reverberated in their allocation of funds. According to the Government Accountability Office (GAO), as well as researchers Livermore, et al. (2011), only 1-2 percent of all federal and state program expenditures for working-aged persons with disabilities are on employment services. The balance is distributed as cash supports. (Livermore, Wittenburg, & Neumark, 2014, p. 3; Wittenburg, Rangarajan, & Honeycutt, 2008, p. 5). Clearly, this paradigm is benefit-centric rather than work-centric and fails to embody the principles of the Americans with Disabilities Act which calls for maximizing self-sufficiency.

Fragmentation of the current disability system

The hundreds of billions of governmental dollars expended on disability support in America are distributed by an enormous hodgepodge of agencies, each with their own priorities and objectives. Livermore, Wittenburg, and Neumark (2014) count a complex network of twenty-one federal agencies and about 190 programs that deliver support to people with disabilities in the U.S. These include initiatives that extend income support, health care, employment, housing, as well as other types of assistance. Moreover, at least ten congressional committees oversee and have authority over the twenty-one federal agencies involved in disability supports (p. 4). Commenting on this overwhelming array of agencies in their 2014 Public Policy Agenda, the National Disability Institute (NDI) lamented that Americans with a disability seeking assistance "have [great] difficulty navigating the web of federal disability programs" (NDI, 2014).

The GAO, in their role as federal agency watch dog, opines that this "patchwork of state and federal disability support programs creates pervasive inefficiencies, including overlaps and gaps in services, misaligned incentives, and conflicting objectives." As way of illustration, the GAO points out that initial disability determination for SSI and SSDI is executed at the state level. Yet, the program is funded almost completely by the federal government. This type of program fragmentation discourages regard for program costs and instead encourages cost shifting. Further, "conflicting priorities, jurisdictions, and objectives create disincentives for agencies to work together" (Mann & Stapleton, 2012, p. 1).

Additionally, this piecemeal and disjointed arrangement of disability support hampers fundamental reform. Implementation of new and transformative programs generally requires collaboration and approval from multiple levels of government and cuts across agencies. These types of opportunities often bind together agencies with varying definitions of disability, conflicting program-specific data, and loosely coordinated statistics. On top of that, American disability policy lacks a specified lead

agency which has a comprehensive vision, and a good grasp of fissures, obstacles, and solutions to disability issues.

Overall, this fragmentation in service delivery, oversight, and funding can compromise the welfare of the disabled, diminish program effectiveness, and squander precious resources.

Complexity

The National Disability Council (NDC) openly worries that the intricacy of SSA rules and guidelines for both of the federal disability programs is completely off-putting to enrollees. The above lengthy and confusing list of work incentive programs clearly illustrates how overwhelming SSI and SSDI policy can be. As a result, beneficiaries are frequently unwilling to take action, stalled by programs they cannot understand.

Following a review of SSDI terminology such as "extended periods of eligibility," and "impaired related work expenses" as well as the program's required "methods of SGA determination" and "reducing countable income through subsidies," the NCD pronounces these fundamentals of SSDI as "simply too much to expect a beneficiary to understand or negotiate." And they label SSDI overall as "just too complicated" (NCD, 2005, p. 81).

The NCD finds the work parameters for SSI as "relatively simple compared to the SSDI program" but nonetheless determines that program stipulations regarding unearned income and assets as "incomprehensible for many beneficiaries." They argue that without expert assistance, "the average untrained person has little chance of understanding and applying" concepts such as deeming, in-kind support, or the numerous resource exclusions (NCD, 2005, p.81).

NCD's overall verdict: "It is unfortunate that the attempts by SSA to address program disincentives… adds to the complexity of the program…The rules become more

and more intricate and the behaviors we intend to reward [such as returning to work] occur less and less often" (NCD, 2005, p. 81).

BUILT-IN DISINCENTIVES TO EMPLOYMENT

Social Security beneficiaries with disabilities must spend months or even years convincing SSA that they are unable to work as a condition of eligibility. Yet, upon their receipt of benefits, SSA begins to communicate to beneficiaries that work is an expectation for them. Congress and SSA have developed a variety of work incentives and special programs designed to encourage beneficiaries to attempt to obtain and sustain employment. Yet SSA's efforts to eliminate work disincentives have often added to the complexity of the entire program, confusing beneficiaries and making them leery of any actions that might unknowingly jeopardize their benefits (NCD, 2005).

SSI Asset Limits

Individuals with disabilities confront serious challenges in accumulating wealth and achieving economic self-sufficiency. Of the almost 50 million Americans with a disability, nearly 60% are asset poor, defined as having insufficient assets to subsist for three months at the poverty level (Lawton, 2011). National Council on Disability chairperson, Jeff Rosen echoes this observation when he writes that among all groups of SSA beneficiaries, SSI participants "face the most severe levels of poverty" (Rosen, 2013).

Unlike SSDI participants whose "ability to save money and accumulate assets is unimpeded by SSA rules….SSI is a means-tested program with limits on both income and resources" (NCD, 2005, p. 82). Eligibility is reserved for only those with few or no assets. The SSI asset threshold prohibits holdings of more than $2,000 per individual or $3,000 for a couple. Any cash, liquid assets, and personal property that an individual could quickly liquidate to cash are deemed resources (Moulta-Ali, 2013, p. 1-2). Certain assets are excluded, such as the recipient's home provided it is where the SSI enrollee resides and one vehicle, if it is necessary for transportation to medical appointments.

Also exempt are household goods totaling up to $2,000, property necessary for any income generating activities, and burial expenses or life insurance policies each totally $1,500 or less (Moulta-Ali, 2012, p. 5). The SSA tallies all other assets including cash, bank accounts, stocks, saving bonds, land, additional life insurance, personal property, and retirement accounts such as 401(k)s and IRAs into the asset limit (SSA, 2014b, What are resources? section). If an individual or family holds countable assets in excess of the limit, they must "spend down" if they are to secure assistance (Greer, 2014, p. 1). Once enrolled, should a participant's assets exceed these eligibility thresholds, the SSI recipient risks loss of both cash benefits and Medicaid health coverage.

The asset limit was last updated a quarter of a century ago in 1989, the single occasion on which it was raised since the 1972 creation of SSI (Moulta-Ali, 2012, p. 5). Further, this threshold is not indexed to inflation, therefore its value has been depressed with time (Rosen, 2013). The asset limit was originally established to ascertain that public funds were not directed toward "asset-rich" individuals. But, today many see this program stipulation posing a significant barrier for SSI participants striving to become self-reliant. They assert that SSI beneficiaries "who do work, generate income, and save" for a more secure future can be penalized for their efforts through the withdrawal of program supports (Lowe, 2010, p. 56).

There is growing recognition that asset limits discourage savings and prevent families from making the type of investments that can help them escape poverty. Just the mere existence of an asset limit telegraphs a message to SSI participants that they should not save nor attempt to accumulate assets (CFED, 2009).

CFED, a national nonprofit dedicated to creating economic opportunities that ameliorates poverty, professes: "Assets limits get it backwards. Public benefits help families get by; savings help them get ahead." Instead of boosting self-reliance, asset limits function as a *disincentive*, discouraging persons from savings for educational opportunities, homeownership, retirement, or seeking employment---all things that could

help them move into a more secure, independent and financially stable position**.** Resource thresholds needlessly protract dependence on government benefits. On the other hand, personal savings are exactly the type of assets that enable families to exit from public entitlement programs (Greer, 2014, p. 1).

Savings also create a financial buffer from unexpected income shocks, such as a death in the family, job loss, or a major home repair. These events leave individuals or families susceptible to predatory lenders and deeper poverty, and could ultimately force them to rely on even greater government assistance. Without savings, struggling families lose their self-sufficiency.

When given thoughtful consideration, it becomes easy to recognize that oppressive asset limits are incompatible with one of the professed goals of public assistance: the promotion of self-sufficiency. SSI program rules discourage asset accumulation yet assets are fundamental to achieving economic self-sufficiency. This incongruity creates a "policy paradox" (Soffer, McDonald, & Blanck, 2010). SSI stipulations pose as a serious obstacle to becoming financially independent and at the same time the program encouraging beneficiaries to seek employment and exit the program.

In his study, "Ineligible to Save? Asset Limits and the Saving Behavior of Welfare Recipients," Rourke O'Brien (2006) asserts, "If we want current welfare recipients to eventually be able to support themselves without government assistance, precautionary savings must be embraced as a way of life. Yet, as long as welfare recipients continue to feel threatened by restrictive asset policies, there is little hope these men and women will partake in formal saving and asset development" (p. 11). Instead policy rules may doom them to living a poverty level subsistence.

The SSDI "Cash Cliff"

A notable share of SSDI recipients who maintain residual work capacity strongly desire to re-engage in the labor force on a full or part-time basis. They aspire to return to a higher income and standard of living, to reap the psychological rewards of enhanced self-worth that is associated with workforce participation, and to reconnect with community life through work. However, many policy analysts acknowledge that beneficiaries are reluctant to do so out of concern they will sacrifice their SSDI benefits and valuable health care coverage. From the perspective of the beneficiaries, the guidelines of the program seem punitive to those who attempt to work and "reduce their dependence" on the federal safety net. Instead the rules seem to "reward" participants who either limit their work level or do not work at all (Smith, 2013, p. 4). Frustration with this program disincentive was expressed by James Smith (2013), Budget and Policy Manager for the Vermont Division of Vocational Rehabilitation, when testifying before the House Ways and Means Committee: "Current efforts to help SSDI beneficiaries return to work at substantial levels are hamstrung by the program's outdated work rules" (p. 2) and beneficiaries feel the program "traps them in ongoing poverty and dependence" (p. 4).

The National Council on Disability (NCD) concurs. They state that "the single most significant disincentive to return to employment in SSDI is the potential precipitous loss of cash benefits", a stipulation built-into the program and dubbed the "cash cliff" (NCD, 2005). The "cash cliff" occurs as a result of earnings above the Substantial Gainful Activity (SGA) level, currently set at $1,040 a month. According to the design of the program, if a participant earns even a single dollar above the SGA established level, an amount below the poverty line, that dollar will result in a complete loss of the beneficiary's cash benefit. The NCD laments that the SSDI program "operates in an all-or nothing fashion"—a beneficiary will either collect his total monthly cash benefit or receive no income support at all (NCD, 2005).

The following example clearly demonstrates how the "cash cliff" can negatively impact a participant's income as he strives to return to work (Smith, 2013, p. 3).

Joe's Job	Joe's Earnings	Joe's SSDI Benefit	Joe's Total Income
Joe takes a part time job earning $13 per hour. He works 15 hours per week.	Joe's total monthly earnings are $838.	Because Joe is earning below $1,040 per month he receives his whole SSDI check of $900.	Earnings of $838 plus SSDI income of $900 equals a total of $1,738 per month.
Joe's boss wants him to work 20 hours per week at $13 per hour.	Joe's total monthly earnings are $1,118.	Because Joe is earning above $1,040 per month he ***loses*** his whole SSDI check, so his benefit is $0.	Earnings of $1,118 plus SSDI income of zero equals a total of $1,118.

.Figure 5. SSDI : "Cash Cliff" from the beneficiaries perspective. Reprinted from the Committee on the Ways and Means, J. Smith, 2013, Retrieved July 22, 2014, from http://waysandmeans.house.gov/uploadedfiles/smith_testimony_61913.pdf

The example above illustrates that should Joe elect to increase his work week by even five hours, his total income will fall by $620 due to the complete loss of his SSDI cash benefit like this as an example. The current design of the program compels beneficiaries to limit their earnings rather than jeopardize the entirety of their program support. For a great fraction of SSDI beneficiaries, a more advantageous financial outcome will be achieved by working part time, holding earnings below the SGA level, and retaining full SSDI benefits and health coverage. It should come as no surprise that less than half of one percent of beneficiaries exit the benefit rolls each year as a result of work activity (Smith, 2013).

Clearly, the "cash cliff" restrains earnings. Until SSDI participants can see that a significant level of employment proves to be of greater financial benefit than not working, attempts to reduce SSDI rolls will prove futile. SSDI guidelines must be altered to insure the work truly pays.

The hesitancy of work-capable SSDI participants to rejoin the work force has additional consequences. There are "losses to the economy in terms of lost output, reduction in tax revenues for the government, and most significantly the loss of gainful careers for younger work capable beneficiaries" (Gokhale, 2013, p. 45).

Fear loss of health care

In order to function independently, many SSI and SSDI enrollees require access to an extraordinarily wide spectrum of medical services and supports which can include specialty therapies, durable medical equipment, adaptive devices, expensive prescription drugs, etc. Additionally, a large number of these beneficiaries face significant disabilities which call for personal attendant services each morning just to enable them to prepare for the day. And for a few, medical treatment is literally a life and death matter. These types of situations make health insurance critically and disproportionally important to a significant portion of federal disability program participants.

Private health insurance policies simply do not offer coverage of the long-term services and supports that allow SSDI and SSI enrollees with these types of challenges to live and work in community. Employer sponsored health insurance, Medicaid expansion, and Healthcare.gov's Marketplace commonly do not include long-term services and supports, durable medical equipment, and comprehensive case management. Or, if they do so, it is only inadequately or for a short period of time. Even the tremendously expensive private long-term care insurance does not cover work-setting services and supports or other special benefits (AAPD, n,d,, p. 1).

This vacuum in healthcare was recently validated through a survey of 1,000 persons with all types of disabilities. The study found that approximately one-third of all participants acknowledged a special need associated with their disability that was not covered by their insurance (Levy, Bruen, & Ku, 2013, p. 103). Therefore, public health coverage is frequently the only affordable option available that provides access to most of the services and supports needed by persons with substantial disabilities.

Individuals with significant disabilities who truly need expanded health care benefits are confronted with a catch-22 situation: they require the comprehensive health care offered by federal health plans, such as "traditional" Medicaid, yet this medical coverage is generally secured only through federal programs such as SSI and SSDI (AAPD, n.d.b, p. 1). Participation in these programs is contingent on having and maintaining a low-income. Thus, many of these individuals must choose unemployment or underemployment in order to answer their need for insurance that satisfies their unique health requirements. Should an enrollee exceed financial parameters, the income and asset limits respective to their program, these health-vulnerable individuals will forfeit their medical benefits. This tethering of health care benefits to the Social Security cash programs creates a "welfare lock" (Coe & Rupp, 2013, p. 1).

Public policy experts and disability advocates believe this desperate need for comprehensive health care and the corresponding tie to SSI/SSDI programs both fuels application rates and discourages beneficiaries from exiting the programs and returning to work (NCD, 2005, p. 99; Coe & Rupp, 2013, p. 1). They further believe it contributes to the rates of dependency on federal disability benefits and the depressed rate of competitive employment for individuals with disabilities. Thus, it becomes a significant employment disincentive within this population.

Numerous studies and surveys verify this employment disincentive. A Cornell University online publication writes that, "According to a national survey, the #1 reason that people with disabilities gave for not working was fear of losing their essential medical benefits." They elaborated, "The fear of losing Medicaid and/or Medicare is one of the greatest barriers keeping individuals with disabilities from maximizing their employment, earnings potential, and independence" (Cornell, n.d.). Health & Disability Advocates concurs, "If going to work means losing Medicaid eligibility, people with disabilities will often opt to not make an attempt to work and just continue to receive SSI" (HDA, n.d.b). Similarly, Moffitt and Wolfe (1992) found that Medicaid coverage is a strong and statistically significant negative predictor of labor force participation and a positive predictor of enrollment in public assistance programs. These findings agree that public health care availability creates a disincentive to work and that this disincentive is even more profound for people with greater health care needs (Levy, Bruen, & Ku, 2013, p. 104).

Lastly, evidence suggests that for many beneficiaries, public health insurance is more valuable than the monthly income received from SSDI or SSI; thus eligibility for public health care creates more significant employment disincentives than the cash benefits from these programs (Levy, Bruen, & Ku, 2013, p. 102). Therefore, people with disabilities often find themselves turning down jobs, foregoing increases in pay, refusing promotions and other economic opportunities in order to maintain access to these vital health services and supports.

To curtail this disincentive there needs to be a severing of the link between public health insurance for the disabled and the federal disability cash benefit programs. People with significant disabilities need a pathway to secure the long-term "services and

supports that allows them to earn to their potential, save for their futures…and achieve the vision of the Americans with Disabilities Act" (AAPD, n.d.b, p. 2).

Chapter 6: Disability Policy in the International Community

Over the last four decades, disability insurance costs have multiplied substantially throughout the international community. A number of Western European countries have struggled to temper ballooning enrollment and soaring costs of these programs, all while supporting those facing work-limiting disabilities. Beginning in 1970, disability insurance enrollment rates in Europe were 2-3 times higher than in the U.S. (Burkhauser, et al, 2014). In an effort to reduce the financial strain, a number of countries instituted widespread reforms that emphasized quickly returning disabled people to the labor force, reducing the number of disability claimants and restricting benefit duration. Although these international reforms yielded varying levels of success, they nonetheless provide a potential pathway forward as America strives to stabilize its currently unwieldy disability support programs. Two nations of particular interest to the current U.S. predicament are the Netherlands and Sweden.

The Netherlands

The Dutch struggle to contain escalating disability outlays began in the early 1970s. This decade was characterized by a notable growth spike in disability rolls, a likely result of their unbridled salary replacement rate. Unlike the policy used by the U.S. at that time, the Netherlands offered an 80% salary replacement rate for an entire year upon the onset of a work-limiting disability. This policy also granted partial payments to those documenting as little as a 15 percent impairment (Gray & Yee, 2014; Burkhauser, 2014).

Recognizing the long-term economic consequences should this continue indefinitely, in the 1980s the Dutch government executed a number of effective disability

reforms. These changes were intended to replace a system characterized by generous monthly allotments and relaxed eligibility standards with one challenging employees and employers to investigate and implement work solutions prior to applying for public assistance. Despite these measures and a 10% reduction in the salary replacement rate, Dutch program spending continued to climb (Gray & Yee, 2014; Burkhauser, 2014).

The next decade brought a considerable narrowing of eligibility regulations and a shift to increased privatization of the disability system through greater employer responsibility. With these reforms, cash transfers and enrollment finally dropped. Companies were now required to cover the first few weeks of employee "sick pay" (Gray & Yee, 2014). Later measures would extend employer responsibility for "sick pay" to one, and subsequently two years (Gray & Yee, 2014; Burkhauser, 2014). This shift in policy created stronger incentives for employers to return medically challenged individuals to the workplace speedily.

The late 1990s saw another rise in program outlays, spurring several new measures intended to stem program growth and encourage work. First came the "experience rated premium" in 1998. This was intended to take the place of the current fixed rate premium, a mandated employer contribution to the disability insurance fund (Gray & Yee, 2014). Under this plan, firms whose workers relied on the disability program at below-average rates would be granted a lower disability tax rate. Alternatively, firms whose workers claimed benefits at above-average rates would be penalized with a higher rate (Segelken, H. R., 2014). This tax incentive ensured employers shouldered a larger portion of the program's direct costs.

The Netherland's next major reform occurred in 2002, with the introduction of the Gatekeeper Protocol. This measure required employees and employers to jointly conceptualize an occupational rehabilitation plan before employee absence reached eight weeks. In order to retain benefits, the compromised employee must demonstrate a commitment to the agreed-upon rehabilitation and retraining requirements. Should the

worker later apply for long-term disability, this rehabilitation plan must be included to validate a substantial effort to return to full employment.

Cumulatively, the "experience rating", the requisite two-year employer-paid benefit period, and the Gatekeeper Protocol fundamentally altered disability policy in the Netherlands. No longer was the focus securing long-term benefits. Rather, accommodation, rehabilitation and continued employment opportunities became the primary goal (Burkhauser et al, 2013). Over the previous two decades, reform has effectively reduced the inflow of persons onto public assistance by a total of 63 percent. The "experience rating" lowered inflow by 13 percent, the Gatekeeper Protocol accounted for 25 percent of the decreased inflow, while strengthening eligibility guidelines reduced inflow by 4 percent. A variety of miscellaneous improvements provided the balance of decreased inflow at 21 percent (Gray & Yee, 2014). Based on these reforms, the Dutch disability system, long perceived as out of control, is now extolled by policy experts as a country which has rectified its past policy blunders and today offers a blueprint for others to follow.

Sweden

In the late 1970s, Sweden's disability insurance policy faced many of the same challenges experienced by the Netherlands: explosive growth of disability applications, lenient initial eligibility requirements and extremely generous benefit packages. Sickness benefits offered an astonishing 90 percent of former wages for anyone exhibiting "abnormal physical or mental conditions" that decreased their work capacity by 25 percent or more (Gray & Yee, 2014, p. 3). The sole documentation required to apply for disability was a certificate signed by a physician. There was no centralized screening provided, so these practitioners conducted these assessments as they saw fit. Those remaining on sickness benefits for twelve months or longer were permitted to apply for long-term disability. Similar to sickness benefits, disability benefits replaced a large portion of lost earnings. Adding to the complexity was the introduction of a new statute

that awarded disability status for those confronting extended unemployment (Gray & Yee, 2014).

The 1990s finally saw a measure of relief, when Swedish policymakers dropped the salary replacement rate from 90 to 80 percent, as well as required firms to cover the first 14 days of sickness absence (Gray & Yee, 2014). The policy changes continued into the next century. In 2003, program administrators were charged with promoting rehabilitation and work supports rather than merely granting cash benefits. Next, the Swedes married their sickness and disability programs, standardized intake procedures, and introduced vocational and rehabilitation assistance earlier in the process (Gray & Yee, 2014). Employers were now tasked with formulating a rehabilitation plan as well as presenting verification that workers received the agreed-upon accommodations. Disability program gatekeepers played a role as well, assuring that applicants fully engaged in their rehabilitation commitments. Failure to complete these obligations resulted in a partial or complete elimination of an individual's monthly income supports (Segelken, H. R., 2014). Combined, these new reforms resulted in a decline in sickness benefit receipts and successfully stifled the inflow of new beneficiaries into the system (Gray & Yee, 2014).

New reforms instituted in 2008 targeted escalating enrollment growth. These changes sought to re-integrate recently impaired workers back into full-time employment. Accomplishing these goals involved a three-ponged approach: rehabilitation, assessment, and counseling. For those demonstrating high risk of exiting to long-term benefit programs, preventative medical evaluations were now conducted at three, six, and twelve month intervals after injury. Combined, these policies effectively raised the rate of client return to competitive employment and shortened duration on the program (Gray & Yee, 2014).

In January 2013, the Swedish government developed and executed an experiment that allows existing beneficiaries to return to the labor force, yet retain the right to re-

enroll in the program at their prior level of benefits. Unfortunately, initial results demonstrate little promise of impacting the work effort of existing beneficiaries eligible for the program. This limited impact suggests that returning beneficiaries to the labor market after a long absence is difficult (Burkhauser, R., et al, 2014; Cook, J. A., et al, 2008).

ANALYSIS

When evaluating these results, it is imperative to note that reform in these European countries started with overly generous programs. For example, the Netherlands and Sweden both offered disability benefits at a salary replacement rate of 80-90 percent. In contrast, the U.S. rate, while variable, is approximately two-thirds of that. Thus, it could prove very difficult for the U.S. to match the magnitude of cost savings achieved by these European nations. Additionally, it is noteworthy that the population of the U.S. is nineteen times larger than the Netherlands and thirty-three times larger than Sweden; this could impact outcomes.

Although the above countries followed their own unique path as they transformed their national disability systems, common lessons were learned from their experiences. Two key reform components emerged that could guide U.S. policymakers tasked with ensuring disability fiscal sustainability: First, the shifting of some costs associated with disability programs onto the shoulders of employers; secondly, the understanding that the most important stage at which to curb growth of disability programs is at the point of entry.

Foremost U.S. expert on European disability reform, Richard Burkhauser, states that "SSDI's most fundamental structural flaw is its reliance on a flat payroll tax for funding" (2013). Under current program policy, the U.S. federal government pays all additional expenses once a worker enrolls in SSDI. This set-up offers employers little incentive to seek workplace solutions at their own expense, such as accommodations or rehabilitation, and instead encourages a reliance on government disability aid. By

contrast, when utilizing an experience rating to determine a firm's tax rate for SSDI, as did the Dutch, firms then incur direct costs when choosing *either* rehabilitation or when quickly passing a disabled worker onto the rolls. This type of incentivizing system is presently used in the U.S. by Worker's Compensation and in some state unemployment insurance programs; therefore, these programs could offer best practices and serve as models. When asked if experience rating could work in the U.S., Dr. Burkhauser advised that the evidence for its success is "not yet strong enough to recommend immediate [system wide] implementation;" yet, it is strong enough that the SSA should promptly begin conducting demonstrations on the concept (Burkhauser, 2011, p. 111).

Secondly, the focus of nearly all modern disability interventions has been on those currently enrolled in the programs. But, European policymakers found that efforts to return long-term participants to the workforce were seldom successful. This is echoed in America's extensive number of work incentive options and the resultant low exit rates. Yet when the Netherlands and Sweden re-focused their program options on reducing the number of *new* enrollees, their enrollment pace began to decline. Therefore, it is imperative for the U.S. to modify its approach and include *preventive* initiatives. SSDI must begin reform at the front end of the disability process. They should pair with employers to "intervene quickly, provide accommodation [and rehabilitation], and empower individuals with work impairments to remain engaged in work" (Burkhauser, 2013). This could be implemented by establishing a gatekeeper process that disallows SSDI enrollment prior to the completion of employer-provided worker's rehabilitative program. Some U.S. experts claim that this type of early intervention "must be at the heart of all serious efforts to stem the tide of new beneficiaries to the SSDI program" (Burkhauser, 2011, p. 82).

Chapter 7: Recommendations

The U.S. Social Security system is presently in grave danger of failing not only its disabled constituency, but American tax payers as well. The enormity and complexity of

the situation calls for a complete restructuring. Unfortunately, an endeavor of this magnitude will entail an extended timeline, a variety of stakeholders (often holding conflicting perspectives), and considerable resources. However, there are several smaller and medium-sized steps policy makers and disability advocates should undertake immediately to yield a measure of relief until a complete reorganization can be properly conceptualized, planned, and executed.

The below table outlines several recommendations to rescue thousands of disabled individuals from the "poverty trap" while concurrently responding to Social Security's fiscal concerns. Each of these has been categorized as *short-*, *medium-*, or *long-term goals*. *Short-term goals* are action steps that can easily be accomplished in the near future (less than six months) while *long-term goals* are anticipated to be fully executed within the span of ten years. A detailed explanation of each objective follows the table.

Short – Term: *(Immediate)*	• Pass the ABLE Act • Replace the SSDI "Cash Cliff" with a Benefits Offset Model • Raise the Asset Limit
Medium –Term: (*One to Five Years*)	• Create a national Medicaid Buy-In • Phase-out the SSDI 24-month Medicare Waiting Period
Long – Term: *(Ten Years or More)*	• Completely re-structure U.S. Disability Policy o Establish a Single Federal Disability Agency o Institute Early-Intervention Models o Expand Employer Responsibility for Disability-Related Costs

SHORT-TERM RECOMMENDATIONS:

Pass the ABLE Act

As discussed previously, current SSI asset thresholds severely discourage people with disabilities from saving for the future, lest their governmental benefits are placed in jeopardy. Recognizing this predicament, U.S. Congressmen Ander Crenshaw and Robert Casey introduced the bi-partisan Achieving a Better Life Experience (ABLE) Act in early 2013. This legislation (H. R. 647/S. B. 313) seeks to provide a path to a more secure economic future by alleviating many of the hurdles to savings persons with disabilities face. This is accomplished via the establishment of a private, tax-advantaged savings account (NDI, n.d.). Under the ABLE Act, individuals and their family would be permitted to place money in this account specifically to assist the disabled individual in maintaining health, living independently, and fully integrating into the community. Funds held in this account are intended to supplement, not substitute, for public assistance benefits. H. R. 647 stipulates that these monies can cover expenses in one or more of the following seven major categories:

- **Housing:** Expenses for a primary residence, including rent, purchase of a primary residence or an interest in a primary residence, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- **Transportation:** Expenses for transportation, including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- **Employment Support:** Expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- **Health Prevention and Wellness:** Expenses for health and wellness, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports,

nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance.

- **Assistive Technology and Personal Support:** Expenses for assistive technology and personal support.
- **Miscellaneous Expenses:** Financial management and administrative services, legal fees, expenses for oversight, monitoring, or funeral and burial expenses (National Down Syndrome, 2013, n.p.).

Housed within Section 529 of the Internal Revenue Code for Qualified Tuition Plans, ABLE accounts adhere to the same guidelines as a traditional 529 qualified tuition program. Earnings from the account are not subject to taxation. Additionally, this income has no effect on eligibility for most federal assistance programs, including SSI/SSDI, up to a specific point. However, once accumulated assets reach $100,000, a temporary termination of monthly benefits occurs. When the account drops below the designate threshold again, benefits are automatically reinstated. In contrast, Medicaid benefits are never subject to suspension, regardless of the account's current value (NDI, n.d.).

Replace the "Cash Cliff" with a Benefits Offset Model

SSDI is long overdue for modifications in program design. Currently, many beneficiaries continue to forego employment or suppress their earnings out of fear of benefit forfeiture. Therefore, policymakers should legislate changes to the SSDI program that will boost workforce participation among disabled participants and lead to their exit from or reduction in their reliance on the program. This can be accomplished through more effective work incentives.

Recovery from an injury or disabling condition, if it occurs, is often gradual. Participants do not usually go from being severely impaired to fully employable in a matter of months. Similarly, exit from the SSDI program often will need to be progressive rather than the "sudden cutoff" as is precipitated by the "cash cliff" (Rich, 2011). An alternative and better fitting approach to SSDI earnings is referred to as a

benefit offset policy or graduated earning offset (Smith, 2013). Here benefits slowly decrease as the beneficiary's earnings increase. The SSI program has such an earnings feature which has been in place of the last thirty years, therefore this is not an "untested approach" (Smith, 2013, n.p.).

The "concept…is…very simple". First, a threshold or earning disregard level for beneficiaries is established. Then, any earnings above that threshold effectively reduce an individual's monthly benefits: for each $2 increase in wages, a $1 offset in benefits occurs. Thus, a person is always better off financially the more they work and earn. It provides a clear and simple incentive" for the beneficiary to attempt to work as much as they are able (Smith, 2013, n. p.).

Removing this barrier to renewed participation in the labor force will spawn direct and positive benefits not only to the SSDI participants themselves but will also generate savings to the SSA and spur the overall American economy.

Raise the SSI Asset Limit

Pass legislation that will raise the SSI asset limit to a modest $10,000 for individuals and $15,000 for couples. Index this asset threshold to inflation to allow the limit to grow over time with the economy. In addition, exempt long-term investments, such as retirement accounts, health savings accounts, and education savings accounts.

The National Council on Disability (NCD), independent federal agency and advisor on disability policy for the President and Congress, rightfully counsels, "While employment is certainly a critical pathway to self-sufficiency, [researchers] argue that people move out of poverty by saving and investing, not by income generation alone" (NCD, 2005, p. 84). Therefore, it is imperative to liberalize the SSI asset limit. By raising this limit to this modest threshold, SSI beneficiaries will be encouraged to pursue work, save for post-secondary education, purchase a home, and save for retirement, all steps that will help them get off, and stay off of public benefit programs.

Studies demonstrate that "asset holding yields improved household economic stability, increased long-term planning, greater educational attainment, reduced inter-generational poverty and civic engagement" (Grinstein-Weiss, Parish, Rimmerman, Rose, & Yeo, 2010, Literature Review section, para. 4). Similarly, the Pew Economic Mobility Project learned that children having low-income parents who were high savers experienced much greater "upward economic mobility than children of low-income low-saving parents" (Hiatt & Newcomer, 2010, p. 5). This research clearly points to the accumulation of assets as a clear promoter of the financial and social mobility for which SSI recipients and the SSA are striving. As a bonus, unlike most other efforts targeting aspects of poverty and requiring complex and costly policy solutions, raising asset limits costs nothing and is expected to increase exit rates of current SSI participants.

NCD predicts this long sought after reform will enhance the "ability of SSI beneficiaries to find and maintain employment and thereby improve *both* their quality of life and the solvency of the program" in which they are enrolled (Rosen, 2013).

MEDIUM –TERM RECOMMENDATIONS:

Create a national Medicaid Buy-In

Congress should authorize a national Medicaid Buy-In which would enable disabled workers to secure comprehensive health care that has been decoupled from the cash benefits of SSI and SSDI. This initiative would replace state Medicaid Buy-Ins and offer uniform health care to many working persons with disabilities. The program would be designed to offer equal access to health insurance; provide health care portability across state lines in support of employment mobility; and decrease participation in federal cash benefit programs (HDA, n.d.a, Point by Point section).

Approximately 17 million Americans with disabilities collect SSI and SSDI federal disability income support payments monthly (SSA, 2014). Many of these persons strongly desire to transition to a greater degree of self-sufficiency through either a

return-to-work or an increased level of work. However, for an individual with a disability, the wish and willingness to work is frequently overshadowed by the fear of losing health coverage that addresses their special health care needs (HDA, n.d.b, Background section). This apprehension is the product of the existing link between cash benefits and health care provisions built into the design of federal programs. Thus, this connection erects a major barrier to employment

Acknowledging this disincentive to employment and desiring to improve workforce outcomes for persons with disabilities, in the late 1990s, Congress authorized the establishment of state Medicaid Buy-In (MBI) programs. This breakthrough legislation was "a key component of a federal effort" to allow participants with disabilities to pursue work and move toward a greater level of economic independence without concern of sacrificing vital health benefits. To be eligible for a state Buy-In program, an individual must have a disability as defined by the SSA, must generate *earned* income, and must meet other financial eligibility requirements established by their state (Davis & Irays, 2006, p. 1).

Current Medicaid Buy-Ins at the State Level

This work incentive option allows states to expand Medicaid coverage to include working individuals with disabilities whose income and assets would otherwise make them ineligible for traditional Medicaid. The higher income and resource limits act as an incentive for people with disabilities to work less restrictively, earn more money, and exit the SSA rolls. Just like a regular insurance program participants pay a monthly premium, usually decided on a sliding scale, in exchange for their Medicaid coverage, thus the term "buy-in."

The state MBI was authorized by the Balanced Budget Act of 1997 (BBA) and the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIAA) and is overseen by the Centers for Medicare and Medicaid Services (CMS). The legislation gives state agencies great discretion in the structure and operation of their Buy-In

program. This "flexibility has led to considerable variation in program design and outcomes among the states" (Kehn, 2013, p. vii).

As of April 2014, forty-six states had implemented this option and created MBI programs. States without a MBI are Florida, Tennessee, Hawaii, Alabama, and the District of Columbia (NDNRC, 2014). The American Association of People with Disabilities tallies that there are approximately 200,000 workers with disabilities currently working and receiving the needed health care as a result of this program (AADP, n.d.b, Proposal Three, para. 1).

Analysis of these state MBIs show enrollees "earn more money, work more hours, contribute more in taxes, and rely less on food stamps than people with disabilities who are not enrolled" (Gavin, McCoy-Roth, & Gidugu, 2011, Plain language summary section, para. 3). More specifically, Lui and Weathers (2007) found that approximately 40 percent of MBI participants increased their wages after enrolling in the program, but these researchers also noted there were "substantial differences across states" (p. 2). Additionally, in a study "Does Access to Health Insurance Influence Work Effort among Disability Cash Benefit Recipients?", Coe and Rupp (2013) validated that Medicaid Buy-In programs ameliorate the aforementioned "welfare lock" disincentive (p. 26). Despite these encouraging results, state MBIs are not without problems.

Although current MBI programs have greatly enhanced opportunities for persons with disabilities to work, the large cross-state deviations in enrollment criteria and some design flaws have limited the effectiveness of these programs (AADP, n.d.b, Proposal Three section, para.2). Additionally, take-up rates in many states are stunted, postulated to be the result of poor public awareness (NCD, 2005, p. 100). Because each state designs their own program, income limits vary from a low of 80 percent of FPL up to unlimited income. As a result, a hopeful MBI applicant may be able to participate in Colorado where the income limit is 450 percent of FPL (Colordo.gov, n.d.), but not in Texas where it is 250 percent of FPL (Texas HHSC, 2011, p. 2) or in Florida which has no MBI at all

(HDA, 2013, n.d.c.). These eligibility inconsistencies can preclude an individual from even considering relocating to another state for a better employment position. A similar issue exists among resource limits which span from a low at the SSI limit of $2,000, up to a completely unrestricted possession of assets (AAPD, n.d.b, Proposal Three section, para. 2).

Participants in many states find the program complex and difficult to understand. And work support features, such as employment counseling are often underfunded. (Gavin, McCoy-Roth, & Gidugu, 2011, Plain language summary section, para. 4). Also, should a participant need time off due to health or any other reason, no grace period exists and the beneficiary is immediately terminated at the end of the month in which their employment status is changed. Additional weaknesses with the state MBIs are the absence of a pathway back to regular Medicaid if a person accumulates resources while participating in MBI and the uncertainty regarding eligibility for Medicaid at age 65 (AAPD, n.d.b, Proposal Three section, para. 3). Together these limitations serve as disincentives, making individuals with disabilities less likely to attempt this option.

The Need for a National MBI

Almost a quarter of a century after the passage of the ADA, the "employment opportunities envisioned for individuals with disabilities has failed to materialize, in part because of the inaccessibility of comprehensive health care coverage" (HDA, n.d.b, Background section). But many continue to trust with the "right tools, Americans with disabilities can live independently in their homes, increase their earnings, and contribute to the growth of our economy as taxpayers, consumers, and small business owners" (AAPD, n.d.a, para. 4).

Capitalizing on what has been learned from state MBIs, it is now imperative to implement a national Medicaid Buy-In where workforce opportunities rather than income or asset limits determine an individual's career direction. And under a national Buy-In, a person's career path will no longer be dictated by keeping health care (AAPD, n.d.b, Proposal One section, para.4). The program should be presented as a work incentive

initiative, rather than another health coverage plan. This would be confirmed by the work requirement of the MBI, something absent all other Medicaid programs. The national MBI will be administered by SSA and overseen by CMS.

The initiative will be strictly limited to individuals who are disabled and working. Every enrollee will be considered a family of one and the health care coverage will not extend to other family members or the beneficiary's children. Participants must meet the Social Security criteria for disability or for those not currently in a federal disability program, by a state disability determination.

Participation financial constraints will be an *adjusted* (employing SSA calculations) individual income at or below 450 percent of FPL. This elevated ceiling is reflective of lessons learned from the state MBIs. Higher income and assets limits attract participants who are more financially stable and who are much more likely to succeed in the job market and not return to disability rolls (Gavin, McCoy-Roth, & Gidugu, 2011). There will be no asset limits. Premiums will be assessed on a sliding scale based on income. Some low-income participants will pay nothing, as is currently the case with federal disability programs; others will be levied 100 percent of program costs. The program will offer disregards for any assets accrued during MBI participation should the individual no longer be able to work. Age parameters will span from eighteen years of age through the SSA's designated retirement age. Grace periods for unemployment that "recognizes the episodic nature of many disabilities" will be instituted. Lastly, there will be a designated avenue back to previous health insurance, minimizing the risk for attempting to return to the workforce (AAPD, n.d.b, Proposal Three section, para. 3).

This national Medicaid Buy-In is anticipated to have the following benefits: enhanced health outcomes, a sense of independence and other social and emotional benefits associated with employment; decreased enrollment in SSI and SSDI; overall lower costs for the government as contrasted to reliance on public cash benefits and total

financial responsibility for medical insurance costs; and the recovery of previously foregone tax revenues due to these workers remaining out of the labor market

Phase-out the SSDI 24-month Waiting Period for Medicare Benefits

Over a ten-year span, Congress should phase-out the two-year waiting period which SSDI beneficiaries must pass through prior to being eligible for Medicare health benefits. Simultaneously, they should institute a pathway which allows for immediate qualification to Medicare for SSDI beneficiaries experiencing a life-threatening illness.

SSDI's primary objective is to afford a safety net for workers experiencing employment interruption due to a serious disability. Regrettably, there exists a hole in this safety net. While SSDI does provide Medicare benefits to its participants, beneficiaries must first endure 24-month waiting period prior to the onset of coverage. In fact, these individuals confront three sequential waiting periods before they are able to access benefits:

- First, SSDI applicants must proceed through the disability determination process overseen by the SSA in order to certify they have a qualifying disability. This often spans months.
- Second, SSDI rules specify that once certified, applicants must wait five months prior to actual enrollment in the program and the commencement of cash benefits.
- Third, once cash benefits initiate, SSDI participants must wait an additional 24 months before the onset of Medicare coverage.

Essentially, medical assistance for the above persons is postponed for approximately three years. Research from the National Health Interview Survey, tied to both SSDI and Medicare, found that during this period "beneficiaries experienced dramatic changes, including marked decline in health" (Livermore, Stapleton, & Claypool, 2009, p. 1). At a time when medical assistance is most needed, SSDI

beneficiaries are often found to be foregoing medications and delaying necessary physician care.

Two important studies showed that "Individuals in the waiting period for Medicare suffer from a broad range of debilitating diseases and are in urgent need of appropriate medical care to manage their conditions" (Center for Medicare Advocacy, 2005). Tragically, an estimated 13% of SSDI new entrants pass away prior to completing the waiting period. Throughout their working lives, these workers steadily contributed to Medicare payroll taxes and yet never realized a benefit (Livermore, Stapleton, & Claypool, 2009, p. 2).

It is believed that immediate access to healthcare would yield better outcomes through improved health and earlier return to the labor force, thus, reducing costs and paring the SSDI rolls. Additionally, with increased returns-to-work would come growing federal payroll and income tax revenues, bolstering the economy.

LONG–TERM RECOMMENDATIONS:

It is clearly time to craft an entirely new vision for America's disability programs. In spite of increased outlays across numerous decades, the U.S. disability support structure is failing many of those it was created to assist. As a result their economic outcomes and independence has eroded. Additionally, these programs are imposing fiscal pressures on our nation's economy. Clearly today's disability paradigm is outdated and fails to fundamentally solve the problems it was designed to address. Adding more small changes will simply increase the complexity of the program. And failure to address the underlying structural issues will perpetuate program inefficiencies and poor outcomes.

This new visions will involve a major structural change that must not be executed in haste and must be based on solid evidence. Poorly conceived policies could harm the disabled population as well as fail to reduce expenditure growth. This restructuring should take place over a full decade and would involve the following:

- The appointment of a central federal agency which would develop disability policy and lead the reform. This will remedy the current lack of leadership and create a single point of contact. It will also entail making disability employment a priority at the federal level and would end policy fragmentation, decrease complexity for participants, and curb growing administration costs.

After this agency is designated, it should commence a substantial demonstration period during which federal, state, local, and private agencies collaborate to design a contemporary disability program infrastructure. They will also seek solutions to old problems, conceptualizing new programs which incorporate one or more of the following principles.

Shifting the focus of disability programs from benefit-centric to work-centric
It is imperative to change program entry criteria away from demonstrating near total disability to emphasizing remaining work capacity. Focus will move from income and in-kind benefits to work supports and economic self-sufficiency.

Implementing early intervention strategies by instituting employer-involvement models
These programs would shift the focus away from currently enrolled beneficiaries and concentrate on stemming new enrollment. Employers would be charged with developing rehabilitation and accommodation plans in the initial stages of the worker's impairment and prior to the worker exiting the workforce.

Progressively expanding employer responsibility for costs associated with employee disability benefits
Building on European paradigms of experience ratings, design a demonstration that will levy surcharges on SSDI payroll taxes for companies with an above average rate of employees progressing onto SSDI roles while lowering the payroll taxes of employers whose workers claimed benefits at below average rates. This would incentivize firms to participate in policies that promote continued work.

The fiscal implications of these reforms could yield federal cost savings by increasing the lifetime earnings of and tax outlays by those with work capacity, reducing dependence on public support, and by ending fragmentation and overlaps in the federal disability programs.

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